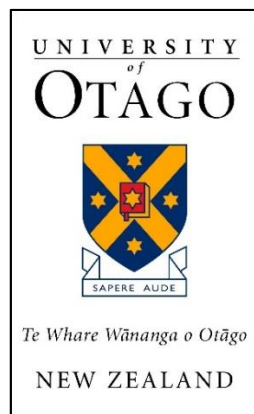


Data entry into a
spinal cord injury registry:
a qualitative exploration of clinicians'
perceptions, influences and barriers

Tracey Croot

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ABSTRACT

Background

In the current health sector there is a demand for high-quality data and research. Registries are a potential source of high-quality data, but whether it is more appropriate for clinicians or clerical staff to enter data remains unclear. In particular, there is a lack of evidence regarding clinicians' roles and perspectives when entering data into a registry. This study aimed to explore clinicians' understanding of registries, as well as their perceptions and experiences of entering data into a spinal cord injury registry.

Methods

Clinicians involved with data entry during a piloting phase for a spinal cord injury registry were invited to take part in the study. Clerical staff with previous data entry experience were also invited. Focus groups and interviews were conducted using a semi-structured interview format. These were recorded, transcribed and analysed thematically.

Results

Sixteen clinicians and two clerical staff participated in four mixed-discipline focus groups and one interview. Three themes were constructed with attention to participants' subjective perceptions, understandings and experiences. The first theme, *'I don't have enough time'*, was the most prominent issue raised by clinicians. They felt they were already under pressure, with an increasing amount of administration tasks to complete on top of their clinical workload, and therefore data entry was not seen as a priority. There was a call for extra clinical staff and designated time set aside for data entry, as well as specific registry roles, such as clinical champions and coordinators. Clinicians thought efficiencies could be made regarding ward system and process changes, such as

improved use of meeting times and streamlined assessments alongside the registry. The second theme, *'The dichotomy of registries; advantages and apprehensions'*, outlined the many benefits clinicians felt a registry could bring, followed by their trepidation and concerns around its relevance, data quality, and use. Previous experiences had a positive and negative effect on participants and featured strongly throughout the focus groups. The third and final theme, *'Engaging the clinician'*, reveals clinicians' perceptions regarding engagement and buy-in to the registry processes. They felt decisions were being made from those in authority without clinician consultation and there was a need for feedback from the registry to promote engagement. Many did not see data entry as part of their role, yet conceded clinicians were best at interpreting data for entry, if it was clinically relevant for them.

Conclusions

These findings indicate clinicians felt too busy to incorporate data entry into their clinical workload. Prioritisation of data entry into a registry was low, yet complex and influenced by numerous elements. These include clinician attitude, previous experiences and perceived difficulties. If data entry was not prioritised, it was not completed. Prioritisation leads to intent, which leads to action. Despite mixed perceptions and experiences, all clinicians wanted the registry to succeed, however, not necessarily through their own commitment. It appeared change was needed at a personal and organisational level.

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Bless your cotton socks. I'm only sorry she couldn't have read the final result,
because I know she would have – every last page.

This thesis is dedicated to the memory of an exceptional woman, my Gran –
Phyllis Jean Rodgers.

He aha te mea nui o te ao

What is the most important thing in the world?

He tāngata, he tāngata, he tāngata

It is the people, it is the people, it is the people

Māori proverb

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LIST OF ABBREVIATIONS

ACC	Accident Compensation Corporation
BSU	Burwood Spinal Unit
EHR	Electronic Health Record
EMR	Electronic Medical Record
FG	Focus Group
HIT	Health Information Technology
NZ	New Zealand
NZJR	New Zealand Joint Registry
NZSCIR	New Zealand Spinal Cord Injury Registry
RCT	Randomised Controlled Trial
RHSCIR	Rick Hansen Spinal Cord Injury Registry
SCI	Spinal Cord Injury
TPB	Theory of Planned Behaviour
UOHEC	University of Otago Human Ethics Committee

1 INTRODUCTION

The health sector has changed dramatically in recent decades and there has been increasing demand for higher quality data and research. There is a growing concept of knowledge translation, which aims to decrease the gap between research and its application in clinical settings. Accordingly, the health information technology (HIT) field has evolved and expanded. Throughout the process of clinical practice, information is gathered, analysed, and acted upon. This information can be used in many forms and technologies. Electronic medical records (EMR), electronic health records (EHR), and registries have all become more prevalent in the health sector and are a valuable tool for producing data.

A registry for evaluating patient outcomes has been defined by Dreyer and Garner (2009) as:

an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purpose(s). (p.790)

Registries can potentially yield high-quality data and it is widely accepted that there are many benefits of comprehensive, robust, reliable, and comparable data in a health care setting (Bickenbach et al., 2013). Registries are key instruments in developing clinical research, improving patient care and healthcare planning, as well as social, economic, and quality of life outcomes (Aymé, Kole, & Rodwell, 2011). Registries also provide an appropriate means for establishing natural history, prevalence, and incidence, and for pooling scarce data. Data from registries can be used to monitor safety, assess clinical effectiveness, and measure quality of care. Registries can be the basis for performing research and are an essential inventory of patients (Brooke, 1974).

It has been argued that data are only as good as the system (or process) that collects it (Grimes, 2010), which suggests data are useful if accurate. For many registries, dedicated data personnel are traditionally employed to enter the clinical data into a registry (Glicklich & Dreyer, 2014). Few registries use clinicians to enter registry data (Barsoum et al., 2012; Cadilhac et al., 2010; Paxton, Inacio, Khatod, Yue, & Namba, 2010; Wennergren, Ekholm, Sandelin, & Moller, 2015). Due to the paucity of research on clinician data entry into registries, it makes it difficult to draw tangible conclusions about clinician involvement.

Even though the importance of a national registry for collecting and processing data for evidence-based clinical practice has been demonstrated in the literature, New Zealand (NZ) has never had a national spinal cord injury (SCI) registry. In 2014, in compliance with the NZ SCI Action Plan, the Burwood Spinal Unit (BSU) trialled two international SCI registries over a 12-month period (Accident Compensation Corporation and the Ministry of Health, 2014; Croot et al., 2015). Clinicians were encouraged, during the feasibility pilot, to enter clinical data into the registries as part of their clinical routine. As it is uncommon for clinical staff to enter data into registries, issues around the data entry process are relatively uncharted. As an addition to the feasibility pilot, this study explores the perceptions, experiences, and elements likely to influence clinicians' data entry into an SCI registry.

2 BACKGROUND

2.1 Overview

This chapter begins with a description of the literature search processes used to identify relevant articles. Following this, a synthesis of evidence in relation to registries, data collection and entry options, focusing on clinician data entry will be presented. A brief description of SCI and the NZ SCI picture will also be given. The participants of this research were involved in the NZ SCI registry feasibility pilot project. This project will be outlined and subsequent pilot recommendations will be noted. The chapter concludes with a summary of literature findings and rationale for my research.

2.2 Literature search strategy

A search for relevant articles was conducted in four electronic databases: Ovid MEDLINE, Scopus, Google Scholar, and CINAHL. The search was limited to articles published in peer-reviewed journals, in English, with available online abstracts, between 1996 and 2017.

Searches were conducted by combining two groups of search terms (text words and subject headings) related to: a) the registry topic and b) data entry. Search terms within each of these two groups were combined with the Boolean term 'OR' (to include any instance of a study where one or more terms applied). The results from these two searches were then combined with the Boolean term 'AND' (to include only studies which included terms related to both 'registries' and 'data entry'). [Table 1](#) provides a list of keywords used for each of these search term groups. Developing a search strategy proved difficult due to highly variable text, keywords, and subject headings across all databases.

Table 1: Literature search keywords

Search term group	Search terms used
Registry	Registr*; Medical; Clinical; Disease; Database; Data repository; Computerized; Medical records systems, computerized; Hospital information systems
Data entry	Data entry; Implementation; Design; Review; Evaluation; User-computer interface; Data collection

Article abstracts were reviewed and those not specifically related to registries or data entry were eliminated ([Figure 1](#)). Duplicates across the databases were also removed. Twenty-four articles were selected for inclusion, based on their applicability to the research questions. Articles were included for review if they reported on or examined some aspect of data entry into a registry or similar system. Both review articles and original research reports were included. Inclusion of studies was not limited by the methodologies used. Subsequently, additional articles which fit the review criteria were also identified from the reference lists of the papers being reviewed, resulting in 43 articles.

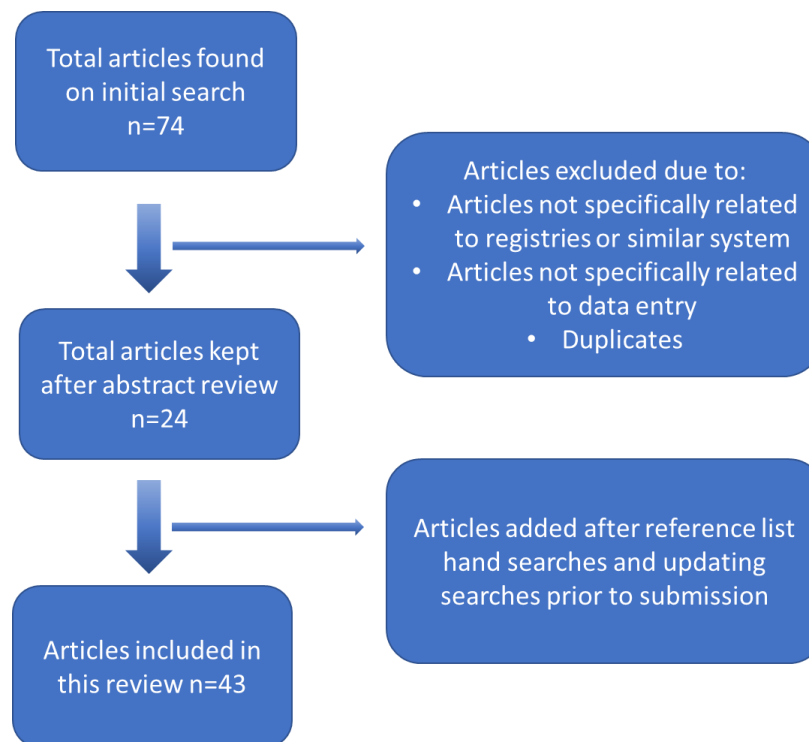


Figure 1: Literature search strategy

2.3 Registries

2.3.1 What is a registry?

The variety of data repository terms are many; register, registries, databases, databanks, computerised records, clinical data sets, electronic data sets, electronic health data, and surveillance systems, to name a few. Even if the search is focused on registries, there are a number of definitions found in the literature (Arts, de Keizer, & Scheffer, 2002; Brooke, 1974; Cadhilac et al., 2016; Dreyer & Garner, 2009; Drolet & Johnson, 2008; Glicklich & Dreyer, 2014). It does appear that despite different terms being used, these researchers agree a registry must use pre-specified, uniform data for a well-defined population. Data should be collected for a pre-determined purpose and appropriately managed security and data privacy strategies are recommended.

The ability to locate articles regarding registries is limited by ambiguity surrounding the terminology. Ideally, a standardised set of definitions of these terms would aid understanding and comparisons internationally. For example,

the terms 'database' and 'registry' are not synonymous. A registry however has potentially more value to physicians, healthcare administrators, and researchers (Drolet & Johnson, 2008). For the purpose of this thesis, the term registry will be used throughout.

2.3.2 Why use a registry?

As the world moves forward to a more technology-based future, electronic health data sets, including registries, are on the rise (Arts et al., 2002; Drolet & Johnson, 2008; Uslu & Stausberg, 2008; van der Veer, de Keizer, Ravelli, Tenkink, & Jager, 2010). Drolet and Johnson (2008) reported a PubMed search for the term 'registry' in July 2007 returned almost 43,000 hits. A present day (October 2017) 'registry' keyword search conducted in Ovid from 1946 to the present day, netted 75,485 hits. This demonstrates that registries now form an important and prominent role in clinical research worldwide.

In 1974, the World Health Organisation examined the purposes of disease registers and outlined eight major purposes they could be expected to serve. They included: identification of individuals; immediate protection of the individual; surveillance; epidemiology; planning, operation and evaluation of services; evaluation of treatment; research and, finally, education (Brooke, 1974).

Glicklich and Dreyer (2014) refine these purposes in their third and latest guide for using registries to evaluate patient outcomes. They acknowledge the need to respect the following four purposes when developing a registry: 1) describing the natural history of disease; 2) determining clinical and/or cost-effectiveness; 3) assessing safety or harm, and 4) measuring or improving quality of care. Both Brooke (1974) and Glicklich and Dreyer's (2014) works highlight that varying multiple registry purposes exist, and their specific scope and emphasis need to be defined when establishing a registry.

They also agree one of the most fundamental benefits of a registry is to be able to provide basic demographic and medical information on the population being studied, which is core to disease control efforts (Brooke, 1974; Glicklich & Dreyer, 2014). In the most basic applications, registries can be used to describe disease and outcome patterns over time. The data points collected can cover demographic, medical, physical, psychological, and social interventions and their outcomes.

Clinical information made available through registries, i.e. diagnoses; admission and discharge dates; outcomes and complications, allows clinical effectiveness to be evaluated. Registry data can add to the understanding of resource allocation and service delivery assessment. Information can assist development of patient flow modelling, giving the ability to explore length of stay or wait-time issues. And importantly, this information can aid patient-centred best practice guideline development. This is all dependent on accurate, relevant, quality data (Cadhilac et al., 2016). By observing registry longitudinal outcome data, the effect of a treatment or any service delivery changes can be documented and inform change. Benchmarking and comparisons between hospitals and health services are possible internationally, as well as potential improvements in preventative care, leading to improved quality of care, patient safety and efficiency (Cadhilac et al., 2016; Chaudhry et al., 2006).

Psoter and Rosenfeld (2013) also suggest registry data are an attractive alternative to original data collection associated with research. Established registries negate the need for multicentre and/or multinational collaborations. They enable data collection from populations over a wide range of geographical locations, giving increased statistical power to rare condition data. Some registries recording less investigated or understood disease processes can provide data to enable deduction of risk factors for outcomes and hypothesis generation (Psoter & Rosenfeld, 2013).

Registries also provide 'real-world' outcomes and experiences, enabling research that will give a higher generalisability and validity. Randomised controlled trials (RCTs) have long stood, with meta-analyses and systematic reviews, at the pinnacle of the clinical research hierarchy (Barton, 2000; Murad, Asi, Alsawas, & Alahdab, 2016). Research studies can be characterised broadly as either interventional (or experimental trials, where the researcher assigns treatments) or observational (where treatments are not assigned by the researcher). To date, RCTs are seen as the gold standard for interventional studies (Zeng et al., 2015). They randomly assign participants into an experimental or control group. The only difference between both groups should be the variable being studied.

There is now recognition that the severely controlled environment of an RCT does not reflect the real-life situation of diverse and complicated patients (Relton, Torgerson, O'Cathain, & Nicholl, 2010). RCTs are therefore vulnerable with respect to external validity (Dreyer & Garner, 2009; Richesson, Horvath, & Rusincovitch, 2014) and alternative sources of information are being sought. Richesson et al. (2014) expand on this, stating momentum is gaining around using more observational studies that reflect the real world. They go on to describe pragmatic clinical trials, which are RCTs measuring effectiveness in routine clinical practice using broader, more generalisable eligibility criteria. Gillies et al. (2014) agree these studies are essentially assessing interventions in real-life conditions, so are more translatable to the general population. By using population-based observational cohort studies, they can help evaluate their effects in broader populations and provide valuable information for future clinical trials (Spigel, 2010). The use of real-world observational cohort study data, potentially obtained from registries, could fill gaps the current RCT evidence could not, and, combined, could offer valuable complementary clinical information.

Another area of promise pertinent to registries includes the increasing use of 'big data'. Stats NZ's Integrated Data Infrastructure is a large research database and an example of big data. Data are collected from government agencies, Stats NZ surveys and non-government organisations, and encompass life event topics such as education, income, benefits, migration, justice and health (Stats NZ, 2018). Big data in healthcare can comprise of massive electronic health data sets, which can be analysed to "improve care, save lives and lower costs" (Raghupathi & Raghupathi, 2014, p. 1). These data sets can include a variety of information from clinical data (medical notes, imaging, lab results), through to machine-generated data (such as vital sign measures), medical journal articles, even social media posts (including Twitter, Facebook and web pages) (Raghupathi & Raghupathi, 2014). As with registries, there are issues with definitions, inclusion criteria, and the software needed to manage and analyse such vast data sets.

Data extracts from registries could be a source for 'big data'. Advantages of 'big data' include the development of predictive and simulation models using historical data. They can inform decisions on the optimal practice across the healthcare continuum. An example of this is the Canadian-based Rick Hansen Spinal Cord Injury Registry (RHSCIR) and the subsequent Access to Care and Timing project. It involved developing a model of health care for patients with traumatic SCI (Noonan, Soril, et al., 2012). With this type of model 'what if' simulated scenarios are used to predict the impact of best practice and policy initiatives on both patient and system outcomes. The model gives the ability to assess the potential financial and functional impact of clinical changes, such as increasing bed numbers or transferring a patient directly from the injury site to specialised care for immediate surgery (Fehlings et al., 2017; Santos et al., 2013). The Access to Care and Timing project used detailed data from the RHSCIR to

investigate these types of queries, which will continue to improve SCI management in the future as it evolves.

By observing population characteristics over an extended period of time, registries offer the chance to obtain answers to questions relatively quickly and easily. Registries may offer potential benefits for clinical care providers, policy makers, funders, researchers, and consumers, through evaluation of incidence, aetiology, treatment patterns, service delivery, and planning, and are therefore a very valuable tool if used wisely.

2.3.3 Types of patient registries

Patient registries tend to be classified according to their inclusion criteria. They typically fall into one of three categories, as described by Richesson and Vehik (2010):

1. Exposure (includes patients who have been exposed to a common medical treatment, a biopharmaceutical product or device, or had an environmental exposure, for example; prescription drugs, prosthetic joint replacements, or chemical exposure);
2. Disease-based (includes patients with the same disease, condition, or syndrome diagnosis i.e. cancer, ischaemic heart disease, SCI);
3. Patient characteristics (includes patients who have genetic traits (like twins) or genetic abnormalities).

Examples of successful national registries include exposure registries such as the NZ Joint Registry (NZJR) (Rothwell et al., 2016), or disease-based registries like Riks-Stroke (Asplund et al., 2011), the Singapore Cancer Registry (National Registry of Diseases Office, 2016), and the RHSCIR (Noonan, Kwon, et al., 2012). All of these have provided ongoing benefits of clinical monitoring and guideline development.

Despite the recent increase in new patient characteristic genetic registries, exposure and disease registries remain the most common types of patient registries (Richesson & Vehik, 2010), no doubt due to being a highly useful clinical tool. These two registry types will be expanded on next.

2.3.3.1 Exposure registries

Exposure registries, including those designed for joint replacements, have proven a highly successful tool for assessing effectiveness, as well as monitoring safety and harm. A well-established exposure registry is the NZJR, established in 1999, which expanded to include all artificial joint replacements performed in NZ (Rothwell et al., 2016). The original driving factor in establishing this registry was the dependency on northern hemisphere “teaching, training and outcome studies for developing their joint arthroplasty practice in NZ” (Rothwell et al., 2016, p. 12). The value, and ongoing success, of this registry comes from its extensive uptake across the entire country. It involves all orthopaedic surgeons in NZ recording detailed prosthesis information for every surgery, therefore providing a surveillance tool to identify issues with joint revisions and failures as soon as possible (Rothwell, Hooper, Hobbs, & Frampton, 2010). Dedicated NZJR staff include a data operators coordinator, supervisor and statistician (Rothwell et al., 2016). Funding has been achieved through annual grants from the Ministry of Health, Accident Compensation Corporation (ACC), and Southern Cross Hospitals, as well as levies per joint registered by private surgeons (Hooper, Rothwell, Stringer, & Frampton, 2009). By demonstrating high compliance for all artificial joints across an entire country, the NZJR serves as a leading research tool, understanding variations in treatments and outcomes. Through feedback of data, it also assists with quality improvement (Rothwell & Wall, 2017).

2.3.3.2 Disease registries

There are a number of successful national disease registries used worldwide for surveillance in conditions such as stroke, cancer, and SCI. Lanzola, Parimbelli, Micieli, Cavallini, and Quaglini (2014) suggest these registries have the capability of streamlining management and improving outcomes. The Riks-Stroke, the Swedish Stroke Register, was established in 1994 to investigate the processes and outcomes of acute stroke patients (Asplund et al., 2011). With all acute stroke hospitals participating nationwide, governmental funding, and a tradition of public access to information, the use of this registry's data leads to continuous quality improvement. Collaborations have led to an international standard set of patient-centred stroke outcome measures, promoting effective evidence-based stroke care worldwide (Salinas et al., 2016).

Singapore has a National Registry of Diseases Office collecting data on selected major diseases and health conditions (National Registry of Diseases Office, 2016), including the Singapore Cancer Registry. Data entry is carried out by officers, known as registry coordinators, who extract and verify relevant information from hospital medical records, then enter it into the registry. This provides Singapore with national data of incidence, cancer burden, and survival statistics.

A well-established SCI registry, the RHSCIR, has government funding to prospectively collect interdisciplinary data from acute and rehabilitation hospitals across Canada. With more than 6000 patients enrolled with traumatic SCI since its inception in 2004, it is one of the largest SCI research programmes in the world (Rick Hansen Institute, 2017). Using standardised protocols and data collection forms, RHSCIR tracks the experiences and outcomes of people with traumatic SCI during their journey through acute, rehabilitation, and community phases (one, two, five, 10, 15, 20 years and beyond). The RHSCIR

operates through clinicians completing paper forms and dedicated staff inputting this data into the registry.

The RHSCIR was established, not only as a national registry, but as a tool to link researchers, clinicians, and consumers to “facilitate clinical research and evidence-based practices in care delivery” (Noonan, Kwon, et al., 2012, p. 23). Multiple studies using RHSCIR data have influenced the direction of traumatic SCI treatment globally (Ahn et al., 2015; Dvorak et al., 2015; Evaniew et al., 2015; Fehlings et al., 2017; Noonan, Soril, et al., 2012; Santos et al., 2013; Street, Noonan, Cheung, Fisher, & Dvorak, 2015). By observing ‘real life’ prospective data, valuable information can determine what treatments or approaches are having a positive effect on those sustaining traumatic SCI.

2.3.4 Strengths and limitations of registry examples

There are myriad reasons why the registry examples provided in the previous section have been a success. They highlight the basic purpose of improving patient outcomes through systematic data collection, and all share the following four features:

- governmental funding
- specific population criteria, with high level uptake across their host country
- strong research connections and development
- and dedicated registry staff.

This means they fulfil Glicklich and Dreyer’s (2014) registry criteria of an organised system collecting uniform data to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined purpose. They have all used their data to: a) feedback to the sites that collect data; and b) identify areas in need of research

which incorporates ‘real world’ experience, therefore boasting superior generalisability and validity, compared to RCTs.

Whilst all these registries have served multiple purposes and driven research, service improvements, and clinical changes for their respective populations, registries remain resource intensive. Establishing population, purpose, registry design, determining data elements and sources, privacy, data ownership, ethics, consent, confidentiality, data collection and entry, quality assurance, education, analysis, and ongoing funding and maintenance, all need consideration and resources ([Figure 2](#)). Of particular relevance to the study



Figure 2: Issues relevant in establishing and maintaining a registry. Includes three main elements central to this thesis: staffing, data collection, and data entry methods.

undertaken for this thesis are the issues of data collection, data entry, and staffing, which are discussed in the following section.

2.3.5 Data collection and data entry processes

Every registry has its own agreed data elements collected for every patient meeting the inclusion criteria, as well as protocols and standards for capturing, processing, and entering data. This ensures the quality of data are accurate, reliable, and comparable. The way in which these data elements are collected and entered into the registry can vary ([Figure 3](#)). Glicklich and Dreyer (2014) edited a two-volume user-guide on patient outcomes, which spanned 669 pages, yet information around ‘procedures, personnel, data sources and data entry systems’ covered less than eight pages. One-and-a-half pages of this discussed EMRs and a paragraph was written on the role of personnel who may enter data, demonstrating little information is available to direct these processes.

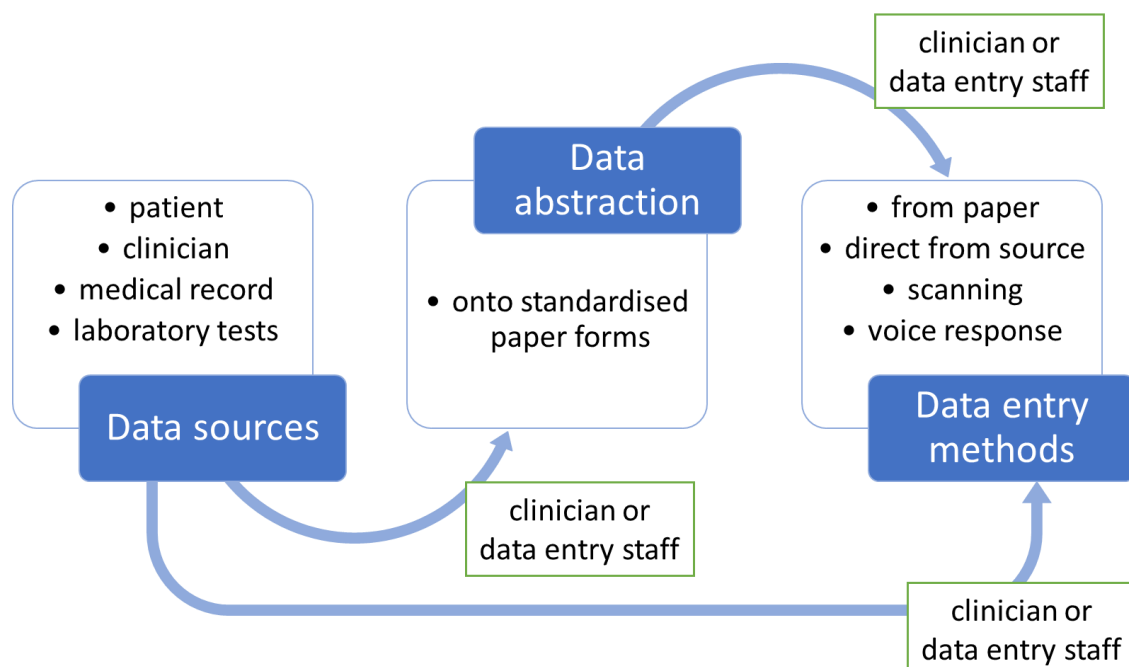


Figure 3: Potential data collection and data entry processes

2.3.5.1 Data formats and sources

Information for a registry needs uniform and systematic collection to ensure accuracy and high participation levels. Data potentially comes in many formats and may be structured, semi-structured, or unstructured (Raghupathi & Raghupathi, 2014). Structured data includes information that fits well into a registry, such as age, gender, length of stay, and clinical outcome measures. They are highly organised, easily searched, analysed and linked to other information. Semi-structured data, however, requires cleaning and reorganisation. This includes, as an example, patient diagnoses that need to fit into a specific category in a registry, such as emphysema under lung disease, or a radiology report interpreted for a diagnosis. It requires some interpretation and cannot be easily searched and linked to other information. The final category, unstructured data, is increasing and can only be processed by specialised data mining techniques. They are often machine-generated, such as an X-ray, MRI scan, or multimedia sources. The data format will impact on how and who will collect and enter registry data, as semi-structured data requires understanding and experience for interpretation prior to data entry. There are many sources of data. Information can be collected from a patient, clinician, medical record, or laboratory tests (Glicklich & Dreyer, 2014). Patient-reported information is specifically collected from a patient for use in a registry and not interpreted by a clinician. From basic demographic data to specific patient self-reported validated outcome measures, there are many issues related to obtaining data from patients directly. When using questionnaires, font, style, reading ability and language need to be considered. The method in which data are obtained (written questionnaires, telephone, computer) will also influence the data. Data reported or derived from clinicians can be grouped into whether the outcome is specifically collected by a clinician for a registry, or if it is abstracted

from other sources (i.e. medical records). The main issue with data abstraction is interpretation error and this is elaborated on in the following sections.

2.3.5.2 Data abstraction

Data can be abstracted from clinical notes, alternative patient, or administrative systems. Obtaining data reported or derived from clinicians from a hard copy set of medical notes, or multiple electronic systems can be a long, difficult, and tedious process. As mentioned in the previous section, it is essential that personnel responsible for this be knowledgeable in their clinical area, as well as following standardised guidelines and definitions to ensure accuracy (Glicklich & Dreyer, 2014). The use of data dictionaries have been shown to be critical in abstracting pertinent information from medical records, to ensure definitions are standardised and allow collection of intended data with minimal error (Asare, Gress, Greene, & Winchester, 2015; Glicklich & Dreyer, 2014). Once abstracted, it can be either recorded on paper, then entered into the registry; or the paper step is eliminated by directly entering into the registry.

Structured numerical data such as dates, blood pressure, or height, are relatively simple to transcribe, whereas converting semi-structured data like free text to fit registry criteria increases error (Lanzola et al., 2014). Incomplete documentation is another issue plaguing data abstraction for registries. Warsi, White, and McCulloch (2002) cite lack of time and training as major contributors for clinicians' poor completion rates for forms in a cancer registry. Other issues for abstraction that may arise include poor handwriting, acronym use, and extracting appropriate information from multiple available sources.

The quality of output from registries will be determined by the quality of the input, a term known as 'garbage in, garbage out' in the field of computer science, or information and communications technology (Grimes, 2010; Lanzola et al., 2014). It is therefore crucial that personnel responsible for data abstraction or data entry be educated around their roles and processes to

decrease the risk of incorrect, even invalid, input data to prevent the faulty, often invalid, output.

2.3.5.3 Data entry methods

Once the data elements have been collected, they can be entered into registries using differing methods: from paper; directly into the registry; or by using scanning systems or voice response. It appears the ideal strategy is yet to be determined and is dependent on such factors as resources and technological capabilities (Barsoum et al., 2012). In this section, two methods of data entry relevant to this study - from paper and direct entry - will be considered. Then issues relating to clinician involvement for data entry versus designated data entry staff will be reviewed.

2.3.5.3.1 From paper

The use of paper forms is still the most common registry data collection method internationally and has historically been the 'gold-standard' (Barsoum et al., 2012; Glicklich & Dreyer, 2014). With paper forms, clinicians enter the relevant details onto standardised forms at the time of the clinical appointment, to be put into electronic format later. Non-clinicians, or specific data entry personnel, can also abstract this information from clinical records, as described in [section 2.3.5.2](#). Many registries use this hard copy paper intermediate step, as a physical back-up can be a legal or mandatory requirement. Data can either be manually entered by designated personnel (data entry staff or clinicians) later, or scanned to extract the data. Whilst this is potentially time-consuming, until health records become fully electronic, this method may be required for some time yet.

2.3.5.3.2 Direct from source

Direct electronic data entry requires resources such as a computer or hand-held device to enter data straight onto a registry (Glicklich & Dreyer, 2014). With the use of mobile devices in the workplace becoming more prevalent, this area

of data entry will continue to grow, as well as the necessary development of appropriate security software and policies.

However, one of the main issues identified with this form of data entry is key entry error rates. When data are entered via keyboard or screen, there are chances of typographical errors, erroneously inserted and missing data. Many studies have investigated this due to the major impact it has on data quality in clinical trials, EMR, EHR and registries (Barsoum et al., 2012; Day, Fayers, & Harvey, 1998; Goldberg, Niemierko, Shubina, & Turchin, 2010; Goldberg, Niemierko, & Turchin, 2008; Greiver et al., 2011; Paulsen, Overgaard, & Lauritsen, 2012; Rind & Safran, 1993; Schaff, Brown, & Lenocho, 2010). Day et al. (1998) suggests that double data entry (the process of having up to two individuals entering data and reviewing discrepancies) aids in recognising the simple random errors, but not all errors can be quantified. Goldberg et al. (2010) believe that despite double data entry being the gold-standard for prevention of data errors, it is costly, labour-intensive and may not be feasible clinically. Greiver et al. (2011) found the use of a data entry clerk to assist clinicians in the use of an EMR, provided a clinically important difference in data quality and was acceptable to clinicians. Strategies for data entry quality improvement are needed to decrease errors. With the recent increase in electronic records, there is potential for development of data entry automation to help address this, with software advances and affordable cost being key.

It is important to note that completing data entry electronically during clinical encounters may not be realistic, as having a device present can be unsuitable or inappropriate in some clinical settings. As a result, paper forms would preside. Some registries (RHSCIR for example) have the option of printing off electronically completed forms in a PDF format to provide the physical paper version for medical notes. This, however, relies on: a) it being in an appropriate format; b) the clinician remembering to print a copy, and c) having

access to a printer – all additional steps and resources that can lower compliance. Direct electronic data entry can be an efficient method, but it does have potential issues with resources, error rates, and clinical appropriateness.

2.3.6 Personnel responsible for data entry into registries

Data can be inputted into registries using designated data entry staff, or by those that collect the data, such as clinicians. As this study is investigating clinician data entry into registries, this will be the focus of the following section.

2.3.6.1 Clinician involvement

As data gathering becomes an important focus for health care, the need for clinicians to be involved has increased. Clinicians act as a potential data source and potential data entry personnel. When looking specifically at research on data entry by clinicians into registries, only a handful of published articles were found (Barsoum et al., 2012; Cadilhac et al., 2010; Paxton et al., 2010; Wennergren et al., 2015). Three of these studies found that using clinicians for data entry had its drawbacks. Barsoum et al. (2012) reported low participation rates with clinician data entry and attributed this to a lack of involvement and oversight from surgeons. Cadilhac et al. (2010) and Paxton et al. (2010) found that due to the need to keep data points to a minimum for compliance, the data set was too small to allow extensive analysis. However, Wennergren et al. (2015) claimed success with surgeon data entry into the Swedish Fracture Register, due to collecting valuable information only, having a user-friendly and intuitive interface, as well as providing relevant real-time information to the surgeons. However, data completeness was not reported.

Barsoum et al. (2012) investigated data entry into a joint implant registry in the United States. Three different data entry options were trialled: paper, direct data entry via online electronic forms, and finally, barcode scanning for implant details. They evaluated accuracy and participation levels for each

method. Data collection was integrated into the current clinical practice, giving responsibility for completion to a nurse directly after surgery. The study was undertaken in three different hospital types: a large academic hospital; a large community hospital; and a small community hospital, each phase of the study undertaken simultaneously until 80-100 forms were completed at each site. No information was gathered in regard to the nurses entering the data: their familiarity in the area; their knowledge; or level of staff turnover; so these potential influences were not measurable. They found that most joint registry expenses were directly related to data collection (Barsoum et al., 2012). If clinicians enter registry data in their current roles, whilst designated data entry staff are not employed, the persistent ongoing cost of increased clinician time for this task adds to the overall cost.

However, they concluded that the low participation rate (52.8%; ranging from 36% to 88% at differing sites) was not only due to the voluntary nature of the registry study, but three other conditions: lack of surgeon involvement, lack of a feedback system, and lack of strict oversight. In contrast, the Norwegian Arthroplasty Register report high participation rates of clinician data entry (96.7% in 2013-2014), despite being non-mandatory (University of Bergen, 2016). Barsoum et al. (2012) suggest having a surgeon or clinical advocate involved in championing the data collection process appears to elevate the participation and compliance rates, which has been supported by others throughout the health information sector (Kolling, Simmen, Labek, & Goldhahn, 2007; Krall, 2001; Paxton et al., 2010; Shachak et al., 2013; Tsikitis, Lu, Douthit, & Herzig, 2013). For the NZJR, orthopaedic surgeons are required to check and sign forms theatre nurses complete after every arthroplasty surgery (Rothwell, Larmer, & Hobbs, 2014). In NZ, this data contribution is coupled with the surgeons' annual registration process, hence their overseeing of the process can be regarded as championing the registry. This

surgeon championing and overseeing role appears to have a positive effect on participation rates, especially at smaller hospitals.

Whilst Paxton et al. (2010) primarily looked at integrating an EHR with a Total Joint Replacement Registry to decrease demand on frontline staff, their data supported Barsoum et al. (2012) in advocating for surgeon involvement and oversight. Both Paxton et al. (2010) and Wennergren et al. (2015) also found a need to ensure minimal burden to clinicians in data collection to maximise voluntary participation. They both reported ongoing feedback to clinicians was essential to show the value of the registry, and provide incentives for participating.

Cadilhac et al. (2010) also emphasised the use of a feedback system for clinicians involved in the Australian Stroke Clinical Registry. Monthly reports were created and sent to hospitals to assess data quality during the implementation phase of this registry. Feedback about the training, supporting documents and data quality were also sent in the early stages to enable revision of processes and materials. By involving clinicians in the implementation processes, clinicians can gather an understanding of the scope and purpose of the registry, and are more likely to engage. In turn, it is assumed clinicians who have bought-in and contributed to registries have a sense of ownership.

Manual data entry of all variables by clinicians for the Australian Stroke Clinical Registry pilot, however, was deemed sub-optimal due to the increased time taken and software issues. Staff opinion and feedback was sought throughout the pilot phase. The aim was to ensure users were involved in evaluation of the registry, a strategy reported to assist with long-term acceptance and optimal buy-in by the staff (Cadilhac et al., 2010). A conclusion from this study was that whilst a small data set decreased the burden on staff, it did lead to limited analysis. Using clinicians to enter data appeared to be

impractical and future technological solutions were recommended to remedy this.

Computer programmes for automated importing of demographic data already in hospital systems are a potential solution to decrease data entry burden. However, these are costly and require specialised support, which can add yet another compounding barrier to implementation. Hye et al. (2015) investigated the use of an EMR to import patient details into an aortic aneurysm repair registry. Demographic details, diagnosis, co-morbidities, procedures and hospital stay data were automatically extracted from the EMR, and supplemented by additional data by the treating surgeon. This decreased data entry burden and simplified workflow, ensuring the additional data entered was minimally intrusive for the surgeons. However, Hye et al. (2015) did not detail costs associated with this system, and considering its use across 30 sites, it can be assumed this import tool and cost was shared amongst multiple facilities. Whilst this is cost-effective for large multi-site registries, smaller registries may struggle to justify the additional cost associated with these technological solutions.

One major benefit of registries for clinicians is the quick access to data for audit or research purposes. Having clinicians involved in the implementation and data entry processes promotes more clinically relevant data points, which can direct the scope and quality of clinical research (Asare et al., 2015).

Wennergren et al. (2015) supports this, reporting that any fracture registry data points deemed not valuable by the system developers, project managers, and orthopaedic surgeons were discarded. If clinicians feel data collected is relevant, and if they rely on this data for audit or research, it would make them more conscious of ensuring accurate and complete documentation. Dedication is likely to rise if clinicians see the benefit of accessing registry information for

their clinical environment. It appears clinicians are more likely to be motivated if they are aware of the usefulness of the information they are entering.

Very few registries have published information on whether they have used formal evaluation methods to establish successful registries (Cadilhac et al., 2010). Due to the minimal research on clinician data entry into registries, the clinician perspectives and user issues within the wider scope of the health information technology (HIT) spectrum will be explored.

2.4 Other areas of health information technology

HIT is on the rise and therefore the terminology and variety of systems associated is expanding. At the heart of HIT is the EHR, defined by The National Alliance for Health Information Technology (2008, p. 6) as an “electronic record of health-related information on an individual, that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization”. The other widespread HIT term is an EMR; medical records that are locally set within one organisation, without the full integrative possibilities of an EHR (The National Alliance for Health Information Technology, 2008). Whilst EMR and EHR are a potential legislative requirement and intended to replace existing paper-based medical records, their data are only considered sources for registries, not registries themselves. However, there is considerably more clinician-related research for these computerised medical information systems that potentially could reveal issues pertinent to registries (Boonstra & Broekhuis, 2010; Cifuentes et al., 2015; Colligan, Potts, Finn, & Sinkin, 2015; Hye et al., 2015; Krall, 1995; Martikainen, Viitanen, Korpela, & Laaveri, 2012; McLane, 2005; Miller, Sim, & Newman, 2004; Viitanen et al., 2011; Walsh, 2004).

2.4.1 Clinician data entry in other areas of health information technology

Looking at this wider scope of HIT, factors influencing clinicians' involvement in data entry are wide and varied. Therefore, assessing how both technical and human characteristics influence the implementation of a new health information system is valuable (Pagliari et al., 2003). Pagliari et al. (2003) stated whilst it was important to ensure the technology is good and user-friendly, it is the ability to influence a behavioural change that will be even more essential. A systematic review by Boonstra and Broekhuis (2010) looked at a decade's worth of articles investigating barriers perceived by physicians when adopting EMRs. It was deemed important to review what physicians felt towards EMRs, as they were the main users of this interface and would potentially influence other users within their area (such as nurses and administration staff). The worldwide adoption rate of EMRs is relatively low and physicians can have great impact on implementation (Boonstra & Broekhuis, 2010). The review identified eight barrier themes across all studies; a) financial, b) technical, c) time, d) psychological, e) social, f) legal, g) organizational, and h) change process. The primary barriers of financial, technical, and time were more often identified and whilst the studies referred to EMR or EHR, these findings may well be similarly applicable to the implementation of registries. The following sections will look at some barriers and benefits of clinicians' participation in HIT, identified in the literature.

2.4.1.1 Financial

Whilst initial costs of developing and implementing HIT can be extensive, there are further ongoing costs associated with upkeep and use (maintaining, modifying, upgrading systems, and accessing data). Support personnel, including coordinators and data entry staff, may also be used. The cost of collecting and entering data can be challenging and potentially prohibitive (Hye et al., 2015). If clinicians enter data in their current roles, rather than

employing designated data entry staff, this increases demand on their clinical time, adding to the ongoing cost (Halladay et al., 2009). Halladay et al. (2009) also noted costs associated with external information technology assistance, training, and the clinical time associated with this. Whilst employing additional registry staff is a known and obvious expense, using existing health professional staff, who often have a higher remuneration than clerical staff, can hide this extra cost.

2.4.1.2 Technical

Technical issues related to clinicians' involvement in HIT ranged from inadequate computer skills of physicians, to the lack of training and support provided (Boonstra & Broekhuis, 2010). Other research has identified alternative barriers, including a lack of electronic data exchange between systems, complexity of technology, and inadequate vendor support (Cifuentes et al., 2015; Edwards, Moloney, Jacko, & Sainfort, 2008; Forsander et al., 2012; Halladay et al., 2009; Shachak et al., 2013). Frustration can arise for clinicians where information systems cannot talk to each other, especially in relation to demographics, hence increasing the workload required to source and input data. Resource limitations, access to computers for example, have also been raised, in combination with increased cost to supply this need (Boonstra & Broekhuis, 2010; Hersch, 2002). Any one of these barriers could deter clinicians from participating or entering data.

2.4.1.3 Time

For most clinicians, the majority of their working day is spent on direct patient contact, regardless of their role within the health system. Therefore, any task that takes them away from patient contact can be viewed negatively. Frequently, clinicians have deadlines and service-based performance objectives, such as ensuring patients are discharged from hospital in a safe and

efficient manner. These will always take priority over data entry of information collected on the patient.

In most studies reviewed for this thesis, time featured regularly as a major barrier. The concept of the 'high cost of physician time' was raised, as was the negative impact of time it took to enter data. This reportedly led to disturbed patient-doctor communication in clinical time slots, with some observing longer appointment times (Boonstra & Broekhuis, 2010). In addition, Lanzola et al. (2014) found that users, whom they did not clearly define, complained of both time-consuming data entry forms and data entry in a stroke registry trial.

It has been said during the implementation of an EMR or EHR, time is required to learn new systems and there is a need for ongoing support (Halladay et al., 2009; Hersh, 2002; Krall, 1995; Miller et al., 2004; Pagliari et al., 2003). Krall (1995) found clinician time 'lost' to data entry varied, depending on multiple factors, including the learning schedule, the experience of the training team, system improvements made, and computer experience. These studies all demonstrate the barrier of time can be multi-dimensional. For clinicians, time is regarded as a highly-prized commodity, so any new system that encroaches on this is likely to be seen in a negative light.

2.4.1.4 Ownership and buy-in

Krall (1998) stated, in relation to EMRs, that "like other individuals, clinicians want to feel invested in projects that require them to change and exert substantial effort" (p.48). He also stated that, in the initial implementation stages, it was critical to ensure clinician input through a variety of channels, such as surveys, focus groups, meetings, and written and electronic communications. If this interaction is "substantial and real" it ensures that clinicians feel heard and valued (Krall, 1998, p. 48). As discussed earlier in relation to registries, clinician engagement and systematic feedback can improve implementation and optimal buy-in by the staff (Barsoum et al., 2012;

Cadilhac et al., 2010; Pagliari et al., 2003). Clinicians can have changes implemented by the establishment or management without consultation, which impacts on their clinical day. This can have a detrimental effect on morale and sense of value. In contrast, being inclusive and working as a team has the potential to improve long-term acceptance amongst clinicians, which is essential for the success of these systems, including registries.

One of the major challenges of clinicians entering data into HIT appears to be the integration of data collection into current, busy clinical workflows (Hersh, 2002). However, some work has shown clinicians who demonstrate a positive, can-do attitude were willing to bear the initial time and financial costs. These clinicians were seen as EMR champions and were critical in getting others to adopt systems and generate benefits (Miller et al., 2004). Conversely, Miller (2004) found those with a less-positive outlook found usability issues more discouraging and showed lower levels of usage, demonstrating the importance of both attitude and system champions.

McLane (2005) also noted the importance of staff outlook, finding nurses' buy-in to an EMR was a pre-cursor to effective use, and ascertaining attitudes of staff prior to implementation would help direct education and development. Work by Pagliari et al. (2003) on a clinician web-based resource provides further support for a strategy of identifying issues early and following up with feedback and responsive modifications. Similarly, Krall (1995) reported markedly improved satisfaction and acceptance of a medical insurance EMR system when clinicians were directly involved in planning and implementation processes.

Martikainen et al. (2012) found, contrary to the popular belief that physicians were disinterested in information technology, a significant number were willing to contribute to development of computer systems. It appears Scandinavian countries have a high exposure and acceptance of these systems,

but lessons can be learnt by involving users in the design phase of a registry. They could influence the procedures and develop solutions to some issues. However, their time needs to be invested early, which may be the ultimate barrier. It seems positive attitudes can be encouraged by seeking and addressing staff perceptions or concerns early in the implementation process.

2.4.1.5 Data quality

The topic of data accuracy has divided researchers. Some believe there are less errors or missing data when well-trained, non-medical data entry staff are used (Schaff et al., 2010; Warsi et al., 2002), while others believe clinicians entering data produce less errors (Barsoum et al., 2012).

Errors can be grouped into three origins: a) errors in the original documentation; b) errors of interpretation from the original documentation; and c) errors in data entry into a system (Goldberg et al., 2008). However, Molenberghs and Kenward (2007) argue missing data (omission rate) in HIT are a major concern and more prevalent than inaccurate data (error rate), which can have detrimental effects on resulting analysis and conclusions. Day et al. (1998) claim the field of data management is full of unsubstantiated statements and errors are more likely to be introduced in the original documentation and not by trained data entry staff. Lanzola et al. (2014) and Warsi et al. (2002) support this and argue non-clinical, well-trained clerical staff would be a good alternative data entry option. Warsi et al. (2002) demonstrated a significantly higher omission rate for skilled personnel entering clinical data over data managers, but felt increased dedicated time for this process would be helpful. Schaff et al. (2010) found increased data variability when abstraction and entry were completed by clinical staff, rather than dedicated database personnel. Despite clinicians' familiarity with the subject areas, it appears that no research currently supports using clinicians as the most accurate or efficient way of entering data. However, the lack of research and conflicting results in this

broad and varied subject area makes it difficult to ascertain the most accurate data entry method.

2.4.2 Potential lessons from health information technology for registry use

In summary, costs, technical issues, and time constraints can be major stumbling blocks for clinicians entering data in HIT. In relation to registries, these could all be applicable.

The financial cost of clinicians entering data may be a more expensive option compared to data entry staff, but is often a hidden cost. If data entry staff are required, this additional cost can be a significant barrier in implementing a new registry, and is frequently one of the first stumbling blocks to appear.

Technical issues, including complexity of technology, lack of electronic data exchange between systems, inadequate computer skills of physicians, or inadequate vendor support, were all listed as barriers in the literature. From a registry perspective, all of these technical issues could also be barriers and, with online registries, a different skill set for clinicians is required.

A lack of time appears to be one of the most consistent barriers noted by researchers in this area. During the implementation phases of an EMR or EHR, time was required to learn new systems and there was a need for ongoing support. Time spent learning the systems in training sessions results in decreased productivity in other tasks, rather than on actual data entry. Again, these issues could be relevant for registries.

Buy-in from clinicians and the data quality are both areas for concern, in HIT and registries. Whilst there is no single solution to these issues, early involvement and detailed training appear to be of benefit.

As these issues have rarely been investigated from a clinicians' perspective, this forms the basis of this study's aims and objectives. As Hersh (2002) stated, the

main challenge in the world of medical informatics is to ensure integration into the busy clinical workflow, which rings true, not just for EMR and EHR, but registries as well. Considering this clinical integration, it is necessary to look at the current NZ SCI Registry implementation process. The following section will discuss SCI and the feasibility pilot on which this research is based.

2.5 New Zealand Spinal Cord Injury Registry

2.5.1 What is spinal cord injury?

SCI is a relatively rare, yet devastating and often life-changing event (Bickenbach et al., 2013). SCI occurs when there is damage to the spinal cord, blocking communication between the brain and body. SCI is often sudden and unexpected. Spinal cord damage can occur through many mechanisms, including traumatic causes such as motor vehicle accidents, sports and recreation, falls, and violence (Kirshblum et al., 2011; Sekhon & Fehlings, 2001; Silva, Sousa, Reis, & Salgado, 2014). Non-traumatic causes often include an underlying pathology: malignant growths, infection, congenital disease, degenerative, or vascular mechanisms (New, Cripps, & Bonne Lee, 2014). Damage to the spinal cord results in neurological impairment affecting motor, sensory, and autonomic functions, such as bowel, bladder, and sexual function (American Spinal Injury Association, 2006). Symptoms of SCI are dependent on the location and extent of the cord damage. In general terms, damage to the thoracic, lumbar or sacral spinal cord results in neurological damage to the lower limbs, commonly known as paraplegia; whilst damage to the cervical region results in damage to all four limbs, known as tetraplegia. Generally, the higher up the spinal cord damage, the greater the level of impairment.

World Health Organisation International Perspectives on SCI (Bickenbach et al., 2013) describe a bimodal age distribution within traumatic SCI, with the first peak being young adults and between 15 and 29 years, and the second peak occurring among older adults (mostly aged ≥ 65 years). As advances are

made in SCI medicine, survival rates improve and life expectancy is now approaching that of the general population in developed countries (Bickenbach et al., 2013). People with SCI frequently require complex long-term multidisciplinary input. It can cause significant burden to the individual, their family and society, as well as having substantial life-long, socio-economic impact (Noonan, Fingas, et al., 2012). Thus, a disease-based registry provides opportunity for collaboration between specialist SCI centres and ongoing collection of quality comparative data for this population. These data are key in assisting improvements in patient care, quality of life, socio-economic outcomes, as well as providing opportunities for research.

2.5.2 Spinal cord injury incidence and prevalence

SCI incidence has been reported internationally from 12.1 up to 57.8 per million (Derrett et al., 2012). On average, there are 80-130 new cases admitted to NZ's spinal units annually (Accident Compensation Corporation and the Ministry of Health, 2014). Only two publications have reported specifically on NZ SCI prevalence or incidence, both limited by inconsistent inclusion criteria and a lack of central data collection (Derrett et al., 2012; Dixon, Danesh, & Caradoc-Davies, 1993).

The BSU has a local service database called SpinData, which was developed in 1983 (Nunnerley, 2015) and continues to be used today. New BSU admissions are entered into SpinData. The scope and data collected have been modified multiple times over the decades. Currently, SpinData is used more as a patient monitoring system for booking follow-up appointments and recording urology procedures. It was deemed inappropriate for expansion as a national registry due to the unsuitable design, poor networking capability, limited data points, and the prohibitive financial cost of solving these issues (Nunnerley, 2015).

Attempting to estimate the NZ prevalence of SCI is challenging, as, prior to the feasibility pilot on which this study is based, no national registry collected this

information. Whilst ACC figures can be utilised, this is not an accurate indication of national prevalence, as non-traumatic cases are not included.

A NZ SCI registry which records traumatic and non-traumatic SCI incidence would therefore assist in determining what resources are required for service delivery. It would also allow tracking of aetiology, determining trends and potential areas in need of improved prevention and intervention. With an ageing SCI population, the ability to track secondary complications and other common SCI-related health-care issues in NZ will have important financial, social, and quality of life benefits.

2.5.3 New Zealand Spinal Cord Injury Action Plan registry pilot and recommendations

The National Spinal Cord Impairment Strategy group developed an Action Plan (Accident Compensation Corporation and the Ministry of Health, 2014) outlining key objectives and actions for NZ's SCI management to ensure the best possible outcomes for those with SCI. One objective of the strategy was to implement a 12-month pilot project to evaluate the utility and feasibility of two international existing SCI registries for NZ. The pilot project was undertaken at the BSU between May 2014 and June 2015 (Croot et al., 2015).

There are two specialist SCI rehabilitation units in NZ. The BSU is a 26-bed rehabilitation facility in Christchurch for those who sustain an acute traumatic or non-traumatic SCI, covering approximately 60% of the NZ population. Geographically, its catchment area covers the area south of Taupo, whilst the 16-bed Auckland Spinal Rehabilitation Unit covers the remaining northern area.

There were obvious cost implications for funding data entry staff during the feasibility pilot, so the trial endeavoured to incorporate the process into clinical practice. Each discipline had a clinical champion identified and trained. Further discipline-specific education sessions were provided to other staff,

regarding data collection and data entry processes. Data points collected during the pilot included details relating to the SCI (mechanism of injury, surgical intervention, neurological assessments), functional outcome measures, complications and key dates from initial injury, through the acute and rehabilitation phases until discharge back into the community (see [Appendix A](#)). A large amount of the data entered in the pilot was gathered routinely by clinicians in the day-to-day management of the patient. The estimated time taken for data entry was dependent on discipline and ranged from ten to sixty minutes per patient (example of webpage in [Appendix B](#)). Data entry into the RHSCIR was completed between November 2014 and March 2015 during the year-long feasibility pilot ([Figure 4](#)).

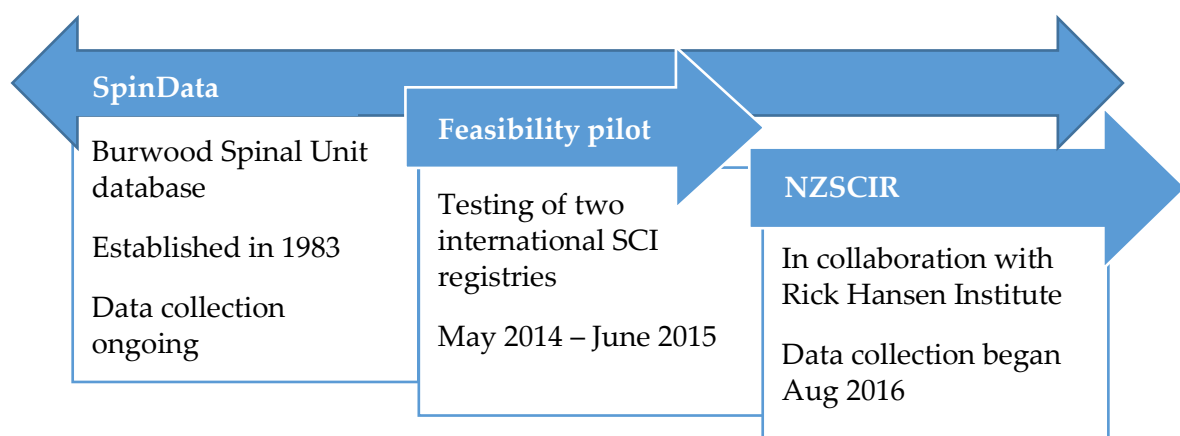


Figure 4: Timeline of SpinData database, feasibility pilot and New Zealand Spinal Cord Injury Registry at Burwood Spinal Unit

Recommendations, based on the findings from the pilot, were to adopt the RHSCIR (see [section 2.3.3.2](#)), as it appeared to meet the objectives of the National SCI Strategy and was suitable for the NZ context. However, the pilot identified a need for a funded NZ SCI Registry (NZSCIR) co-ordinator and data entry hours at each site, for education of staff re data entry, registration of new cases, and data accuracy (Croot et al., 2015). It was noted that more work was required to understand the barriers and limitations of clinician data entry to facilitate a positive sustainable implementation.

2.6 Justification, aims and objectives

As the world of health informatics expands, it seems reasonable that clinician involvement will influence the success of the applications. This literature review has revealed a dearth of evidence around data entry into a registry and other HIT from a clinician perspective.

Whilst registries are becoming more popular and their data forming the catalyst for change, in research and then integration into clinical practice, the most effective way in which data are collected and who enters this data remains unclear. Clinician understandings or experiences have been limited to the likes of electronic health or medical records.

Motivated by the need to ensure the newly implemented NZSCIR is established with clinician input, the present study aims to explore the understanding and experiences of staff entering data into a SCI registry. To date, there have been no studies of this kind in NZ and very limited research internationally. As such, the perceptions of clinical staff and the understanding of how a registry is clinically integrated are unknown.

The present study aims to address this gap by exploring opinions and experiences of clinicians entering data into a SCI registry in the BSU and its impact in a clinical setting. The specific objectives of the study are to investigate:

1. What are clinicians' perceptions and understandings of registries?
2. What influences clinicians entering data into a SCI registry?

Understanding this process will be of benefit for the ongoing national implementation of the NZSCIR. These findings will also assist any service wanting to investigate the influence clinicians have in the use of a health registry and give productive, positive foci for registry implementation in a multitude of settings.

3 METHODOLOGY AND METHODS

3.1 Overview

This chapter outlines the methodology and methods for this study. The paradigm of constructivism will be explained, as well as the study's design and analytical approach. Rigour elements and ethical issues recognised in relation to this research will be described.

3.2 Theoretical background

Research can be broadly grouped into three different frameworks – the quantitative approach, the contrasting qualitative approach, and a mixed methods approach, which blends the two. At the most basic level, quantitative research involves numbers as the primary data source, whilst qualitative utilises words. Quantitative approaches pursue relationships between numerical variables, with the aim to explain or predict. This potentially allows for more broader generalisability of findings across a wider population, but conversely, this framework produces shallower, less-detailed data (Braun & Clarke, 2013).

In contrast, qualitative approaches use the written and spoken language as data, with the emphasis on exploring meaning from more detailed accounts. The results gleaned from this deeper, richer data however are harder to generalise. Qualitative approaches can be seen to generate theories from an inductive perspective (working with the data from the bottom up, moving from specific observations to the broader theories), whilst quantitative tend to test theories using deductive perspectives (working from the top-down from broader theories narrowed to a hypothesis, confirmed through an observation). Qualitative research is not interested in numbers or even a single answer, but is

fundamentally concerned with meaning – aspects of the social and psychological world (Braun & Clarke, 2013).

In more recent decades, a third paradigm, mixed methods research, has been developed. Whilst there is recognition that the type of research question will determine the choice of paradigm, the idea that qualitative and quantitative approaches are mutually exclusive has been criticised (Creswell, 2003; Newman & Benz, 1998). Mixed methods research uses aspects of both approaches of data collection and analysis within a single study (Braun & Clarke, 2013). It has become popular in the social and human sciences (Creswell, 2015), as most social research at some point will involve both inductive and deductive reasoning processes along the continuum between the two. By adopting a mixed method approach, it allows for greater understanding of the research topic through use of qualitative and quantitative components. However, ultimately it is the nature of the research question that will dictate the most appropriate paradigm.

As my research objectives were to explore clinical staff's perceptions and understandings of registries, and what factors influenced staff entering data into an SCI registry, I was looking centrally at human experiences and understandings. As this has not previously been explored, it led me to qualitative methodology that would provide richer data that could fully explore the research questions.

Crotty (1998) suggests that the way we see the world will shape how we research the world. He advises, when developing a research proposal, to consider the four basic elements that underpin the research process: epistemology, theoretical perspective, methodology, and methods (see [Figure 5](#)). Each element influences and directs the following element, giving justification, consistency, and transparency to the process.

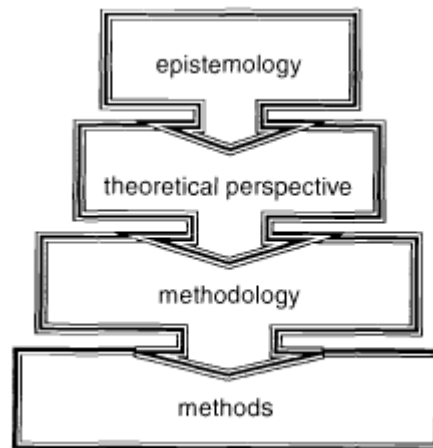


Figure 5: The research process (Crotty, 1998, p. 4)

3.2.1 Epistemological position

Creswell (2003) states, all three broad research approaches (as described in [section 3.2](#)) contain philosophical assumptions about knowledge claims, design, and research methods. The philosophy of knowledge has two important elements: epistemology and ontology. Epistemology is a way of understanding and explaining how we know what we know, whilst ontology is about the nature of things and what things are. Crotty (1998) believes, whilst ontology does not need to be explicit in the schema of Figure 2, it does tend to emerge conceptually with epistemology, informing the theoretical perspective. Every researcher brings their own orientation to their subject, which is shaped by their ontological and epistemological position (Marsh & Stoker, 2010).

I have adopted the perspective of constructivism to underpin my research. This paradigm uses the metaphor of construction to demonstrate knowledge is built by individuals. According to constructivism, there is no one truth, but a non-foundational view of knowledge (Braun & Clarke, 2013) which accepts peoples' meanings as being socially constructed. Guba (1990) believes the constructivist paradigm uses subjective interactions to access realities, as they believe realities are constructed in the minds of individuals. Guba (1990) explains the researcher and the participant's subjective interactions are co-

constructed into a single interactive entity and inquiry findings are literally created by the interaction between the two.

Social constructivism extends the construction of meaning concept to include the social interactions and is seen as situation dependent (Creswell, 2013). This epistemological position fits with my research questions for both the participants and myself as the researcher. It allows me to gain knowledge by asking about my participants' perceptions, understanding and experiences with the registry. My participants' perceptions of registries are intertwined with a variety of social and environmental forces, like past experiences, understandings, peer interactions, and support levels. Knowledge and reality are co-constructed through social interactions and relationships. It allows the participants to share their experiences with each other and develop a dialogue, which aims to give voice to the participants and inform new understandings, by building or constructing meanings.

3.2.2 Theoretical perspective

It is important to ensure my constructivist philosophical stance is made explicit, including how my background influenced processes throughout my research. As a dual clinician-researcher, it was expected that I would bring my previous experiences into my research, firstly as a SCI rehabilitation physiotherapist, and later, a feasibility pilot coordinator and finally, a registry coordinator. I had worked alongside all my participants as a clinician, for up to 15 years. I shared certain experiences with the participants regarding the topic of investigation, and as such, I felt this provided me with an 'insider' perspective (Le Gallais, 2008). I shared characteristics, roles, and experiences with the study participants. I had direct experience of the registry process I was researching. I also had to be aware of not misinterpreting my subconscious assumptions as understanding. My position as a researcher was not a passive role, but one of an active agent. It involved interpretation, which

in turn was based on my own “assumptions, values and commitments” (Braun & Clarke, 2013, p. 285), which the stance of constructivism allows.

The critical thinking skills I used daily as a physiotherapist helped me balance and build meanings from participants’ perspectives, as is appropriate in constructivism. The social constructivism perspective allows the assumption that knowledge is a human construction and there is no absolute one truth or reality (Creswell, 2013). For this qualitative research, the constructivist view is preferred as it encourages the interaction and influences of the researcher to construct meaning and understanding. Constructivism allows the interactions between the participants and the researcher to co-contribute to the overall research, which is shaped by individual experiences (Creswell, 2013; Guba, 1990), which is an appropriate paradigm to use for this research.

3.2.3 Qualitative Methodology

There are multiple diverse methodological strategies available for researchers within the qualitative paradigm. Wolcott (2001) conceptually describes 19 different strategies as branches of a tree, with participant observation at the core. Creswell (2013) agrees that there are a baffling number of options, listing 13 authors’ differing sets of classifications in his qualitative design text. Put simply however, the five major strategies are Ethnography, Phenomenology, Grounded Theory, Narrative, and Case Studies. In Ethnography, the researcher starts with a theory and develops a complex description of the culture of groups, their values, behaviours and beliefs through observation (Creswell, 2013). A Phenomenological approach investigates the lived-experience of a group who share a phenomenon. It looks at subjective interpretations of their own world, and the researcher describes the essence of the phenomenon, enabling an understanding of what it was like to experience the phenomenon (Creswell, 2013). A phenomenological researcher can bracket themselves out of the research to partly set aside any personal experiences of

the phenomenon. Thirdly, in Grounded Theory, a researcher focuses on a process or action and aims to develop a theory through carefully planned steps, generated from data gathered over time (Creswell, 2013; Crotty, 1998).

Narrative research studies collect and construct detailed stories about a person's lived experience by collaborating together. Popular approaches include biographical, auto-ethnography, life history, and oral history. Case Study methodology, according to Creswell (2013), involves "the study of a specific, real-life, often unique case, over time, using multiple forms of data. A well-defined group, person, project or process is described and studied, giving an in-depth understanding to the case" (p.97).

However, none of these approaches related well to my research questions. Phenomenology was an area of initial interest, yet I was keen to explore participants' understandings and perceptions of registries, as well as elements influencing their use, whether they had used the registry or not. As Phenomenology requires all participants to have experienced the same phenomenon, this methodology was dismissed, as not all participants had been involved with entering data into the registry.

Another option considered for this study was the use of Case Studies. However, it became apparent case study was not an appropriate methodology because some professional discipline groups were very small; in addition, the feasibility pilot was already complete, so it would not have been possible to comprehensively observe the participant group.

To investigate the unexplored area of clinicians' opinions and experiences of entering data into a SCI registry, I decided the best approach would be a qualitative methodological approach, using focus group data collection methods and thematic analysis as the analytic tool of choice. Braun and Clarke (2006) argue thematic analysis should be considered a specific qualitative approach in its own right, and this will be described further in [section 3.4](#).

3.2.4 Methods

There are a variety of qualitative data collection tools available. Creswell (2013) describes a continually expanding number of qualitative data forms in the literature. However, they tend to fall into one of four categories of information: observations (as a participant or non-participant); interviews (from interviews to focus groups; closed-ended to open-ended structures); documents (journals; letters; public documents; medical records etc.), and audio-visual materials (photographs; compact discs; Twitter messages; video recordings etc.) (Creswell, 2013).

The often-favoured tool of choice for healthcare research is focus groups (Gill, Stewart, Treasure, & Chadwick, 2008), with a semi-structured outline. Focus groups collect qualitative data from a homogenous group of people in a group setting, through focused conversation (Krueger & Casey, 2009).

Advantages of focus groups over observations, or individual interviews in clinical research, are wide-ranging. They provide a forum to gather a range of views and understandings of an issue, from a number of participants, within the time constraints of busy clinical workloads, effectively and efficiently. Focus groups have been helpful in assessing why people chose to use, or not use, a product (Krueger & Casey, 2009) and therefore, relates to my questions around the use of registries. The socialisation that occurs in focus groups was ideally suited to this project. As little prior research has been performed in this area, the ability to promote discussion and debate amongst those who may have differing opinions and perspectives was essential. Krueger and Casey (2009) stated focus groups were an appropriate way of understanding staff perspectives of barriers and incentives for productivity, which also directly relates to my research aims. Focus groups give participants the option of asking questions of each other, and to agree or disagree with each other, providing richer, more-detailed data.

Limitations of focus groups include being difficult to manage and organise, participants easily getting 'off topic', and the need to identify and handle the challenges of group dynamics (Braun & Clarke, 2013; Krueger & Casey, 2009). Demographic, power, or experience variables can influence a group's interaction, creating an environment where they may feel hesitant to talk (Krueger & Casey, 2009; Stewart & Shamdasani, 2014). However, as focus groups are an important tool for "discovery and exploration" in social science (Stewart & Shamdasani, 2014, p. 49), and an appropriate data collection method for the social constructivist view, meanings could be forged in discussion or interactions with others in the group (Creswell, 2013). I therefore felt it was an appropriate method to address my research questions.

3.3 Research Design

3.3.1 Participant recruitment

Potential participants needed to have been a clinician or clerical staff member at the BSU, during the feasibility pilot project period (May 2014 – June 2015) and been invited during the pilot to enter data into the registry (clinical staff), or had previous experience entering data into a service database (clerical staff). Recruitment used purposive homogenous sampling, as described by Onwuegbuzie and Collins (2007), to find individuals based on similar or specific characteristics. It was essential to this research, clinical participants had been invited to enter data, and they were asked to participate, whether they had actually entered any data or not. This was to enable exploration into the barriers to data entry. Clerical staff who had experience using alternative registries were also invited, as these participants could add to the debate on the barriers and benefits of data entry for clinicians, as well as give feedback on previous experiences.

Eligible staff members were approached via email by a third party, with a participant information sheet and consent form ([Appendix C](#)) attached. If a

response was not received within the first week, a reminder email was sent. If there was no response after the second email, they were contacted via phone by the third party. Participant details were forwarded to the researcher once the signed consent form was received. The participants were then contacted by the researcher to obtain basic demographic information ([Appendix D](#)) and to arrange potential times for focus groups.

3.3.2 Data collection

My aim was to have between three to eight staff members in each focus group, as Braun and Clarke (2013) recommend this number for richer discussion and found this group size easier to manage. For any participant not able to attend any of the arranged focus groups, a one-on-one interview was offered.

3.3.3 Semi-structured question development

To ensure relevant topics would be explored, an interview guide was designed and trialled, following Braun and Clarke's guidelines (2013). It involved thorough discussion with my supervisors and other researchers experienced in focus groups ([Appendix E](#)). The initial question was broad to encourage discussion, with prompts listed to ensure topics of interest were covered (Creswell, 2013). This allowed participants to construct the meaning of the situation, which is consistent with a constructivist approach (Creswell, 2013). Changes were made to ensure questions were open-ended to ensure participants' views were heard and they addressed the study objectives.

3.3.4 Focus group methods

The focus groups were held at three different Burwood Hospital meeting rooms, adjacent to the BSU, to ensure participants were out of their clinical area. A neutral observer was present in all focus groups to give moral and technical support and guidance where needed. I facilitated all focus groups, having read relevant focus group papers, observed another research focus group, and discussed my role with experienced qualitative researchers.

It is acknowledged focus group members' demographics and personality can influence interactions (Stewart & Shamdasani, 2014) (i.e. power balances with a mix of senior and junior staff being present may influence/suppress junior staff from commenting), so an effort was made (where appropriate) to balance focus group participants evenly. I placed participants with seniority in different focus groups to those junior members of the same discipline. I moderated the groups, aiming not to participate in discussion but guide it. I encouraged participation from all members, and facilitated differing opinions and viewpoints, giving each member a voice, regardless of rank or discipline.

Clerical staff participated in the focus group discussions. As the study's main aim and objectives were regarding clinicians' perceptions, understandings and data entry influences, the questions and discussion essentially covered the clinicians' role. Throughout this study, participants are referred to as clinicians, unless otherwise highlighted.

All focus groups were digitally recorded (audio and video). Field notes were made throughout, by myself and the observer, including body language, verbal nuances and group interaction observations. As a qualitative interview guide is not a fixed document at the beginning (Charmaz & Belgrave, 2012), it was revised immediately after each focus group was completed. All audio recordings were sent to a professional externally contracted typist for a verbatim transcription. [Table 2](#) describes the transcription conventions used for this study.

Table 2: Transcription conventions

Symbols used	Meaning
[]	Used to insert words for clarification or rephrasing by researcher
...	Speech omitted for clarification
-	Pause or hanging phrase resulting in an incomplete sentence
“words in double quotes”	Participant quote
‘words in single quotes’	Verbatim participant quote within a quote

To anonymise the data, each participant was given a pseudonym. As the number of male participants was small, unisex names were used to make gender identification difficult. Any identifying information was removed or generalised (e.g. names of people, places, or service) to further ensure participants’ anonymity.

3.4 Data analysis – thematic analysis

It is necessary to define certain concepts used within this analysis at the beginning of the process.

- Data corpus: All participant demographic information, focus group, and interview transcripts.
- Data set: The transcripts of four focus groups and one participant interview used for coding.
- Data item: One focus group/interview alone.
- Data extract: A coded block of data from a participant’s focus group/interview.

- Node: A collection of references about a specific area of interest. The references are 'coded' sources from transcripts.

Thematic analysis was developed by Braun and Clarke (2006, p. 79), who named and claimed the systematic approach for “identifying, analysing and reporting patterns – themes – within the data”. Thematic analysis allows exploration of how experiences and realities operate in society, as well as the ability to generate “unanticipated insights, comparing similarities and differences across the data set and offers an in-depth description and analysis of the data set” (Braun & Clarke, 2006, p. 97). Thematic analysis is relatively unique as a data analysis method, in that it does not prescribe methods of data collection, theory paradigms, or epistemological framework (Braun & Clarke, 2013). As I was looking at a relatively unexplored area, I felt thematic analysis was an appropriate analytic approach.

The advantages of thematic analysis include its flexibility and the fact it is relatively quick and easy to learn. It requires covering basic data handling and coding skills, without being bound to a theoretical construct (Braun & Clarke, 2013). As a first-time qualitative researcher, I felt this approach allowed flexibility, but remained underpinned by my theoretical assumptions of constructivism, as discussed earlier. In addition, this study has an inductive approach, which was not driven by my theoretical interest in the area. It required a process of coding the data without trying to fit it into a pre-existing coding frame, theory, or my analytic preconceptions (Braun & Clarke, 2006). This choice of analysis allowed me to answer my research questions by constructing a detailed interpretation of clinician understandings and experiences of registries.

Thematic analysis only provides methods for data *analysis*, and as such, followed a six-phase process (Braun & Clarke, 2006) applied to the obtained data, as outlined in [Table 3](#).

Table 3: Thematic analysis process

Phase 1: Familiarising yourself with your data

I reviewed each transcription thoroughly whilst listening to the original audio recording and corrections were made as necessary. I watched the video recording to confirm speakers when audio was unclear. I re-read each transcript repeatedly to familiarise myself with the data. I repeatedly listened to recorded debriefing sessions with my observer after each focus group, and regularly viewed field notes I made subsequently. Initial ideas were noted.

Phase 2: Generating initial codes

The second phase consisted of systematically coding the entire data set, looking for interesting and relevant ideas in relation to my research questions. The five formatted transcripts were loaded onto the data management tool, NVivo 11 Software (QSR International Pty Ltd, 2015). Text segments containing noteworthy and similar information were highlighted and assigned to a node. A session was held with my two supervisors where we all coded a single data item. This allowed us to discuss and compare codes, until a consensus was reached (investigator triangulation, (Patton, 2002)). The initial codes were used to code the remaining transcripts, but if new ideas were found, then these were given new codes.

Phase 3: Searching for themes

Codes with similar descriptions or concepts were grouped into potential developing themes. Code labels were modified as needed.

Phase 4: Reviewing themes

Once the themes had been developed and collated, a thematic map was generated. The themes were checked against the coded data extracts and entire data set to ensure a good fit. Definitions of themes were sent to my two supervisors, with examples of codes for verification. These definitions were then discussed in a one-on-one meeting with my primary supervisor. I re-read the transcripts and field notes to ensure no themes were missed.

Phase 5: Defining and naming themes

In the fifth phase, ongoing analysis to refine and define each of the themes. Names were allocated to the potential themes and together they conveyed the key analysis of the research.

Phase 6: Producing the report

For the final phase, the most vivid and compelling examples of themes were extracted, ensuring they clearly illustrated the themes they represented. Analysis continued throughout the writing of the findings chapter. It was important to relate this back to the original research questions and literature review, producing a final analysis report.

3.5 Rigour

To ensure that my research was conducted with rigour and was trustworthy, I followed Lincoln and Guba (1985), who describe a series of techniques to address this. To establish trustworthiness, there are four elements they state as critical: credibility, transferability, dependability, and confirmability. These will be discussed next in relation to my study. In addition, the recently developed TACT framework – Transferability, Auditability, Credibility, and Trustworthiness (Daniel, 2017) was reviewed to outline the steps to support enhanced rigour ([Figure 6](#)).

3.5.1 Credibility

Credibility, ensuring the study measures what it is intending to measure, also known as internal validity, can be reached using many techniques. My research included the following techniques:

- Prolonged engagement. I spent a prolonged period of time (up to two years) working on the registry feasibility pilot, in the setting where the participants of this study worked clinically, which gave me understanding of the culture, setting, and many influences. I had developed a rapport and trust with the participants.
- For this study I could be considered an ‘insider’. The concern was I may not appreciate participants’ perspectives due to my preconceptions. I felt I was empathetic and sensitive during focus groups, however conversely, I had to be conscious of the potential influence I had on the group’s responses and how those responses could be interpreted. I endeavoured to mitigate this by having a neutral observer present in all focus groups and regular debriefings with supervisors and peer groups. In addition, I answered the questions prior to undergoing the focus groups to ensure I reflected on my position ([Appendix F](#)) and a journal was used to note any reactions or biases throughout the research process.

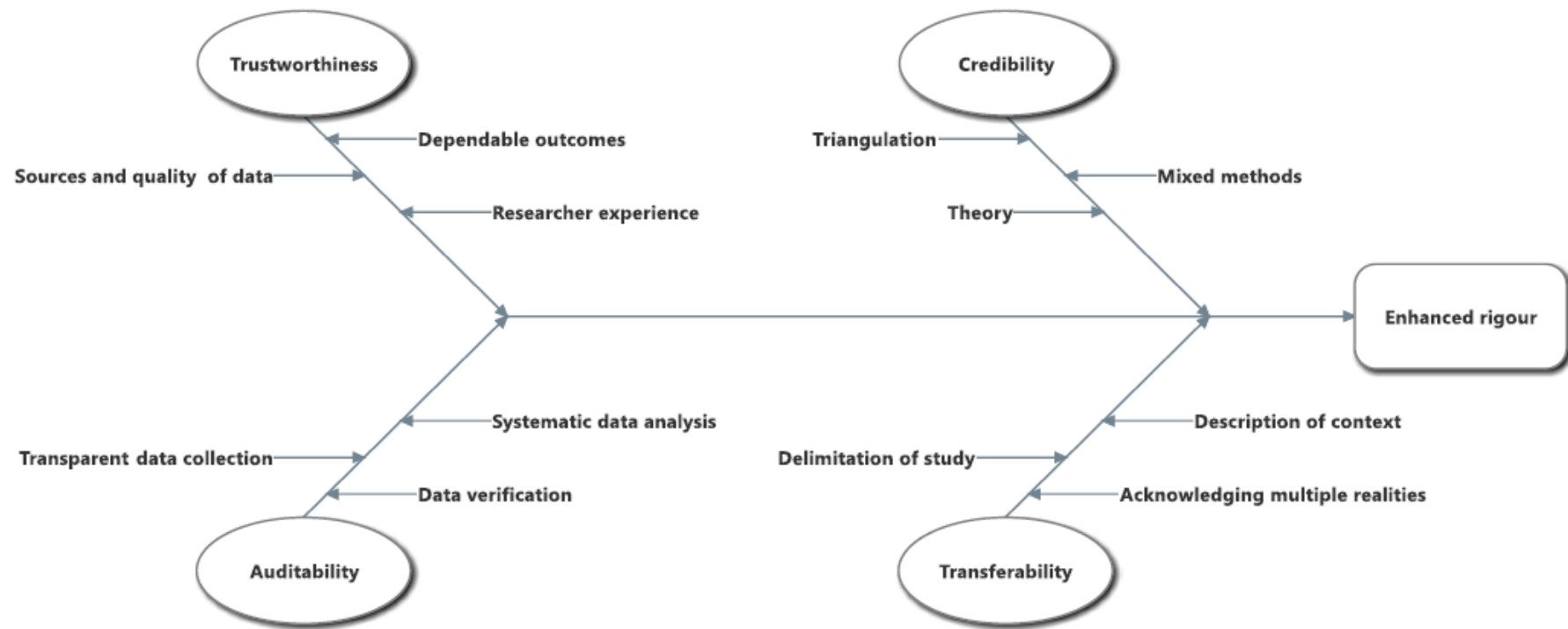


Figure 6: The TACT framework: Trustworthiness, Auditability, Credibility, Transferability (reproduced from Daniel (2017)).

- Persistent observation. I was able to identify the characteristics and elements that were most relevant to staff, hence providing depth. Using field notes and video analysis allowed emphasis to be placed on areas of most concern and passion amongst participants.
- Peer debriefing. By discussing the analysis with the observer of the focus groups and my two supervisors, it allowed me to be aware of my biases, perspectives, and assumptions towards the data. It also provided me with an opportunity to discuss my thoughts and feelings about the focus groups and the information obtained. Throughout the data collection and analysis processes, I needed to reflect, especially in relation to being transparent about my own pre-conceptions and biases in relation to the topic.
- Negative case analysis. During analysis, I searched for contradictory patterns emerging in the data, aiming to explain or account for the majority of cases.
- Referential Adequacy. Data that I deemed not relevant, and therefore did not analyse, was archived for later analysis after the preliminary findings were established. This method tested the validity of my findings.

3.5.2 Transferability

To achieve a type of external validity, a “thick description”, as described by Lincoln and Guba (1985), was used to detail how the research was undertaken, to enable others to ascertain if the conclusions reached by my research is transferable to their situation. Daniel (2017) agrees description of context is one important aspect for transferability. Other considerations were recognition of the multiple realities existing, and rationale for choices made (delimitations) throughout the study were detailed.

3.5.3 Dependability

In order to determine dependability, an external audit of the process and findings was undertaken by a researcher not involved with my study, at the conclusion of the analysis process. Daniel (2017) expresses this as trustworthiness, linking dependable outcomes with sources and quality of data with researcher experience. Whilst I am an inexperienced researcher, I was able to draw on advice from two experienced supervisors throughout the process.

3.5.4 Confirmability

An audit trail, a detailed description of the processes undertaken throughout the entire research process, was performed. This included decisions and steps, including rationale, for my design, collection, analysis, and reporting.

Reflexivity is a way of systematically reviewing my position and effect on the construction of knowledge throughout the research. I was sure to document how I thought my preconceptions, values, beliefs, position, and assumptions influenced the analysis. By coding a transcript with my supervisors, I was ensuring similar understanding of the words was achieved. Likewise, having an observer attend the focus groups allowed feedback on nuances like body language and group interaction.

3.6 Ethics

3.6.1 Ethical approval

Ethical approval for this study was obtained through the University of Otago Human Ethics Committee (UOHEC (Health)). An application was submitted on October 12, 2015 (H15/106). This application was reviewed, and a three-year approval was granted by UOHEC on October 16, 2015 ([Appendix G](#)).

As part of the ethical review process, Māori consultation was undertaken. No participants identified as Māori, but the BSU Māori Health Service (Ranga Hauora) was consulted and no cultural issues were identified.

3.6.2 Ethical considerations

Despite the study being identified as low-risk by the UOHEC, attention to ethical issues was still taken very seriously throughout the research. I was aware that my position as a dual researcher-clinician could have an ethical impact. There was a potential risk of coercion – colleagues feeling as if they should be part of my research due to my existing relationships with them. As a result, I recruited participants through a third party (see [section 3.3.1](#)).

I did not wear a uniform and was explicit to state the research was undertaken as a University of Otago student, not as a clinician, or registry coordinator. The aim was to ensure I did not appear as a clinician, as I wanted to obtain rich data from their open and frank discussion. I wanted the participants to feel comfortable to say both positive and negative things about the registry.

The typist employed to transcribe the focus group transcripts was regularly used by local researchers and signed a confidentiality agreement. Any other potential ethical issues that arose were discussed with my supervisors at our monthly meetings. These issues will be discussed fully in [section 5.5](#).

4 FINDINGS

This chapter will present the findings identified from the transcripts of the four semi-structured focus group interviews and one in-depth interview. The analysis focused on participants' opinions and experiences with registries, and what barriers or enablers influenced their data entry process. Three main themes emerged: *I don't have enough time*; *The dichotomy of registries: advantages and apprehensions*; and *Engaging the clinician*. These will be described in detail in the following chapter.

4.1 The participants

Of the 27 eligible people approached to participate in the study, 18 consented. Reasons for not participating included: being on maternity leave, being too busy, or leaving the service. Taking into consideration clinical commitments and rostering of the participants, four mixed-discipline focus groups (FG1-4) were organised over a 5-week period. One participant was interviewed separately (FG5), as they were unable to attend any of the arranged focus groups but wished to participate.

Demographics and characteristics of the participants are outlined in [Table 4](#), [Figure 7](#), [Figure 8](#) and [Figure 9](#). Characteristics are combined to help prevent identification of participants.

Participants were predominately female (n=13, 72%) and the age of the group ranged from 25-29 to 65 years plus. Four clinical disciplines were represented, including medical (consisting of spinal registrars, consultants, and surgeons), nursing, occupational therapy, and physiotherapy. Clerical staff (n=2) were included in this study to add to the discussion on data entry. Non-participants were all female (n=9) and all disciplines, except nursing, were represented.

Table 4: Participant characteristics

Variable	Participants (n=18)	Non-participants (n=9)
Gender, female (%)	13 (72%)	9 (100%)
Discipline (% of sample)		
Physiotherapist	6 (33%)	1 (11%)
Medical staff	4 (22%)	1 (11%)
Nursing staff	4 (22%)	0 (0%)
Occupational therapist	2 (11%)	3 (33%)
Clerical staff	2 (11%)	2 (22%)
Social worker	0 (0%)	2 (22%)

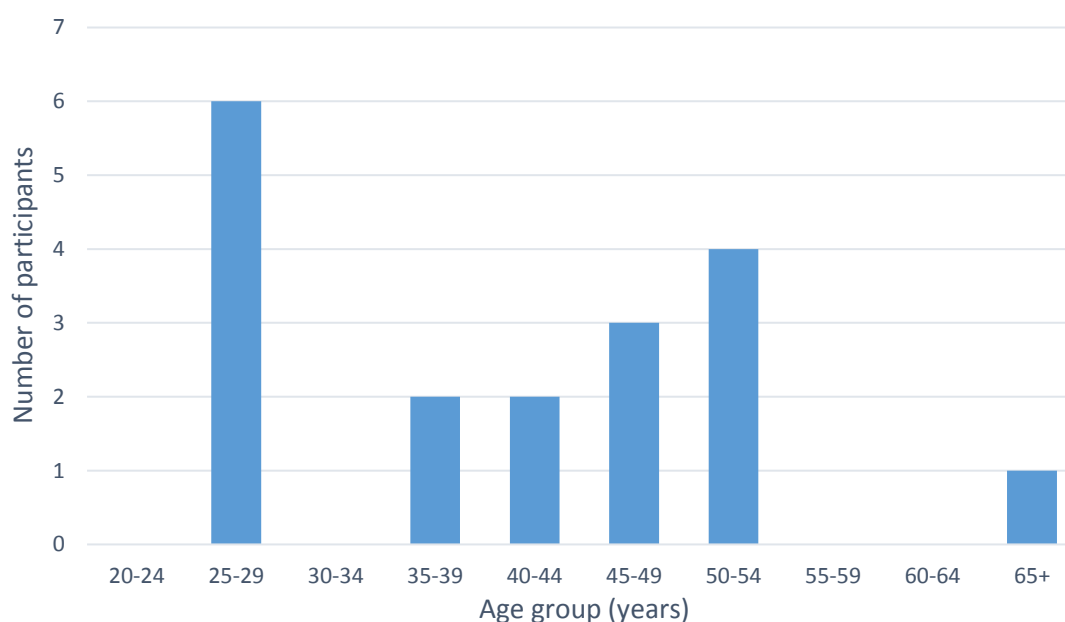


Figure 7: Age range of focus group participants

The median (IQR) time since first clinical qualification was 12 (6 – 24) years, with seven participants having more than 20 years' clinical experience. The level of experience participants had within the BSU was varied, with one-third having up to four years, one-third having five to nine years, and the final third having 10 to 20+ years BSU-specific experience. Over half (n=9, 56%) of the 16 clinician participants had undertaken post-graduate study.

Fourteen of the 18 participants had been invited to enter data into the registry during the pilot. Of the invited clinician participants, only one had not entered data during the pilot. Nearly half (n=6, 46%) had only entered one patient's data, whilst the remainder completed four or more patients' data ([Figure 8](#)). It is not known how many data sets the non-participants had completed.

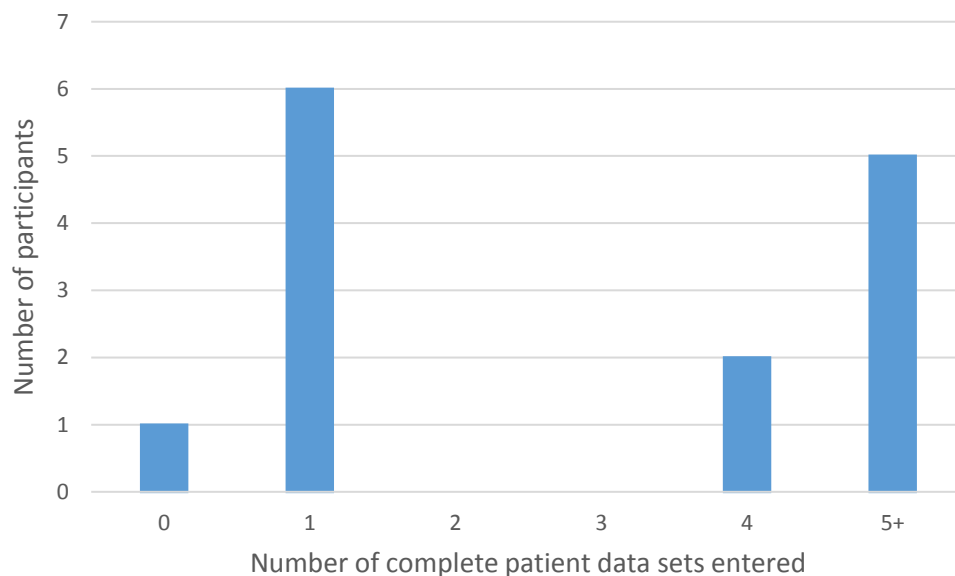


Figure 8: Number of completed patient data sets entered by participants

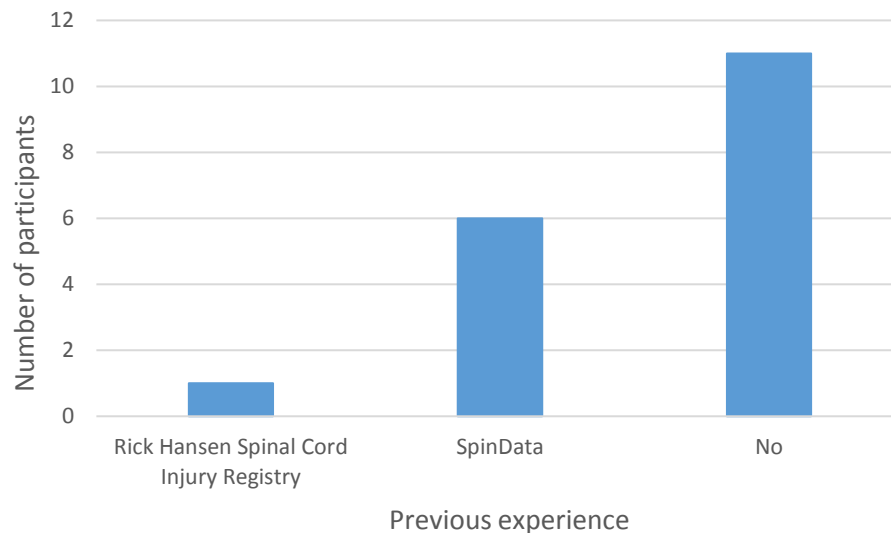


Figure 9: Participants' previous data entry experience

Participants were asked if they had any previous experience with an alternative registry or database ([Figure 9](#)). Sixty-one per cent (n=11) had no previous experience, whilst 33% (n=6) had worked with the BSU service database, SpinData. Only one participant had prior experience with the pilot project registry, the RHSCIR. Those who had not been invited to enter data for the pilot project (n=4) all had SpinData experience.

4.2 Overview of themes

There were three themes that emerged from the focus group transcripts ([Table 5](#)), each comprising of smaller sub-themes. In line with the social constructivism approach, themes were constructed with attention to participants' subjective perceptions, understandings and experiences with the registry.

Table 5: Summary of themes

Themes	Subthemes
'I don't have enough time'	<ul style="list-style-type: none">• It's a matter of priorities• More staffing needed• Systems and processes need changing
The dichotomy of registries: advantages and apprehensions	<ul style="list-style-type: none">• Benefits a registry can bring• Suspicion and apprehension
Engaging the clinician	<ul style="list-style-type: none">• Clinician buy-in, engagement and understanding• 'We didn't become clinicians to be administrators'• Clinician's willingness to change

The first theme, *'I don't have enough time'* relates to clinicians' need to prioritise tasks and how they identified patient-contact tasks were prioritised over data entry roles. Most staff saw data entry impacting on their time and felt they may be able to include this in their working day if staffing was increased. Staff identified potential changes to improve efficiencies, increasing time available to perform the data entry.

The second theme, *'The dichotomy of registries: advantages and apprehensions'*, relates to concepts around clinician-perceived benefits of having a SCI registry at the BSU. This is offset, however, by the sense of trepidation they hold around relevance, quality and reliability of data, along with the potential misinterpretation and uses of registry data.

The third and final theme, *'Engaging the clinician'*, covers the perceptions around clinician understanding and buy-in to the registry pilot project. It also reveals whether clinicians believed data entry was seen as part of their role and their willingness to change.

The remainder of this chapter will elaborate on these patterns and develop the three themes.

4.3 Theme One - I don't have enough time

The most prominent theme was a lack of time. This was a major issue for all participants and was the most mentioned barrier to data entry during the focus groups. The first sub-theme describes clinicians' decision-making regarding priorities in their clinical day. Priorities were made due to the multiple time pressures exerted on clinicians. A second sub-theme follows, concerning the need for more staffing. Here, participants described the potential staffing that may assist in the success of a registry. Lastly, the third sub-theme discusses changes needed to improve systems and processes to potentially enable clinician data entry into registries.

4.3.1 It's a matter of priorities

A number of participants believed data entry would take them away from their primary role as a clinician. Many said there were too many tasks in their working day already, and stated their priority always sat with treating the patient.

And I wish that I was a better person and was more pro-active in filling in forms on computers but I'm not. I prefer to be out with my patients, helping them, that's why I'm in the job I'm in.

Taylor, FG2

But you know, at the end of the day, we are here for eight hours and it's not something that I would hang around work for to necessarily do or... I've got enough stuff to do.

Jules, FG1

Participants indicated the need to assess what was most important to perform daily, as there was not enough time to achieve everything. Whilst many saw the long-term benefits of a registry, they stated it was the immediate patient-related daily tasks that took precedence.

I guess the challenge would be people's view of it as a priority. You know, I think clinicians tend to find something that they believe will be clinically relevant for the patient. It might be treating a patient, writing a report, whatever, so [data entry's] always going to be low on the pecking order of activities to be done. It's like statistics. I mean statistics are invaluable for looking at the amount of volume you're putting through, but do you think I can get people to do statistics? No, because at the end of the day, there is a patient to see and that is their priority.

Mackenzie, FG3

Allied health participants conveyed the organisation-imposed time-limits, resulting in an extensive number of daily tasks. Occupational therapists revealed, as an example, the extensive list of processes and paperwork associated with a single piece of equipment for trial and purchase.

Sometimes we're challenged as well, like 'why didn't you do this?' or 'why didn't you do that?' or 'how come you don't consider this?' and it's like, 'Well, actually, because I was doing A, B and C, I couldn't get down to X, Y and Z'. I couldn't even get halfway down the list of things I wanted to do, you know, I haven't been able to. Sometimes we're lucky if we finish a wheelchair trial, do you know, by the time someone's ready to leave the door, you think 'How is that possible?' Well, it's because we were this and this and this and this and now you want me to enter in Rick Hansen, well that means... there'll be maybe one other job I don't get done.

Cameron, FG1

Physiotherapists also reinforced this, stating there were a range of services they were involved in, not just treating a patient in the gymnasium. These all had associated processes which took time. Equipment trials and orders, discharge summaries, and referrals all added to their administration time, which was time not necessarily protected for clinicians during their working week.

You know like, we don't have that many hours in a week to do all of that, when we get an hour, if we're lucky, of admin actually protected, a week.

Jules FG1

Medical staff stated they were already overstretched, they had "100 things to do in a day" (Gabriel, FG4), and entering data into a registry was not a priority for them. Participants gave examples of the increasing workload and high expectations of staff, as described by Mackenzie (FG3):

It's like the cup's full, you can't add any more drops to our cup, we will burst, you know. We were talking about this yesterday, just in terms of our massive clinic load now. It's gone from six years ago being eight clinics, now it's 21, with no extra [staff]. How do you ... then add another task into our days?

4.3.2 More staffing needed

Associated with the reported increase in workload in the previous sub-theme, participants identified a lack of additional staffing influenced their ability to complete data entry into the registry. They felt more clinical staff were needed and suggested a dedicated registry coordinator be employed, and specific staff identified as clinical champions.

4.3.2.1 More clinical staff needed

Participants identified if they were expected to perform data entry for the registry, then additional staff would be required to assist with ensuring clinical tasks were completed. Throughout the interviews, participants agreed the health service was becoming more demanding, yet the corresponding staffing was lacking.

It's like that with all health, isn't it, you're always asked to do more without getting the [staff] to also match the increase in what you're expected to do.

Cameron, FG1

Many felt if data entry was being imposed on them and was felt to be worthy by the “elite governance group” (Drew, FG3), then there should be supports and resources put in place to ensure its success. Many thought the issue could be resolved with an increase in dedicated staff to support the changes.

I totally support the fact that if it is of that much value then they need to give it adequate [staffing] to ensure it's done to a competent level, that it's worth then taking data from, and that needs to be backed up with staff.

Drew, FG3

Some felt data entry would add to the stress clinicians were already feeling. This additional data entry was seen as excessive and beyond what was expected from clinicians. If data were valued, then participants said they needed to have the support of more clinical staff, or specific registry personnel.

4.3.2.2 Dedicated registry personnel needed

Many participants felt there needed to be a dedicated person responsible for data entry. Alex (FG2) stated “there has to be somebody whose job it is”, which was unanimously agreed upon in their group.

From a data entry perspective, everyone saw dedicated staff as a potential positive. It was felt clinicians would welcome a person entering data to decrease their workload. Lee (FG5) was keen on having someone who “is there to try and minimise the impact it has, so that any impact it does have, is all relevant”.

A registry coordinator, someone responsible for the general day-to-day running of the registry, was also desired. “We need leadership on the ward, to be honest, but we need someone leading this project, but bringing everyone along.” (Drew, FG3). Some described the need for prompting clinician data entry and a coordinator being present “at the coalface” (Taylor, FG2), so they were a visible reminder.

Others felt support on the BSU in the form of a clinical champion was required. Lee (FG5) described the need for clinical champions “to ensure that their colleagues continue to contribute and provide some supportive encouragement on a collegial basis”. Lee felt this approach would be more popular, rather than being dictated to by management.

4.3.3 Systems and processes need changing

Discussion around the need to change systems and processes, formed the next sub-theme. This covered issues around decreasing the doubling up of work, having protected administration time, and paperwork and procedural changes to improve efficiency. Incorporating it into practice was a recurrent topic.

The issues lie with the current systems enabling the use of the Rick Hansen registry so, you know, it's not necessarily creating more time, but being smarter with time and taking away some of this superfluous work and you know, making sure that we're not doubling up on roles and make sure that we've got adequate paperwork that enables accurate input of information... making sure that current paperwork reflects what's required for the registry and so it's a review of our current paperwork for initial assessments, a review of our current paperwork for discharge summaries and for outcome measurements, so that it becomes easier to ensure that it's there and it's really seen and available for putting into the registry.

Pat, FG2

It appeared there were systems and processes clinicians felt could be improved to help with data collection and entry. Many felt there were patient assessments performed by multiple disciplines, at different times, to achieve the same outcome. These inefficiencies were an issue for some, as they felt that time could be better spent on other tasks. Multi-disciplinary meetings were also highlighted as an area for improvement and a potential source of information for the registry. Some suggested meetings were not operating at their full potential due to lack of direction and poor structure. Some believed the registry could be incorporated into a new meeting structure to allow efficient data collection or entry to benefit all parties.

Paperwork issues were debated and it was evident changes to incorporate the registry into the current systems and processes would be beneficial. Some discussed changing assessment and discharge forms, or even designing new versions to allow easier transcription of data into the registry. The physiotherapists described summary forms they constructed which helped improve the process for them, but they also described practices preventing utilisation of spare time. Examples given included the need for two therapists to be present in the gymnasium at any one time, even if only one therapist was involved in treatment. Whilst they needed to be in the gym for safety reasons, they were unable to complete data entry due to computers being in another

area. They felt time efficiencies could be made by refining these processes with either more resources (mobile computer access) or a change in systems.

It appeared incorporating the registry into normal clinical practice was an important topic and possible solution highlighted by clinicians. Many felt this was the way to ensure ongoing success and buy-in. Participants suggested, rather than creating something new, attaching it to existing processes, such as ward meetings or current paperwork, would be more successful. They felt it would then be passed on to new staff entering the area, as it would be integrated into usual practice. Others, however, said that even if it was incorporated into practice, it would still need a non-clinician to drive the process.

Some aspects participants mentioned as barriers within their practice, related to the registry's user-friendliness. Challenges that resonated with most participants included: downloading authorisation certificates onto hospital computers, difficult password creation and basic login problems, data point definitions, and inputting issues. These were all noted as deterrents for inputting data into the registry and many felt there were steps that could be simplified. The paper versus online data collection debate saw a range of responses, with most disciplines favouring paper to eliminate the computer aspect.

My experience in terms of the user-friendliness of [the registry] I found it incredibly difficult... I don't know if you remember all those dropboxes that we had to use and trying to work out what the dropboxes were for, was ... I'll use the word 'nightmare' because it was ... Because of that, I never actually ever got round to inputting more than one person's data because the next time I went to do it, I just had to re-learn it all over again and I don't think we ever got to the bottom of understanding what some things were for and what other things weren't and where, and how to put information in. So that was probably a big hindrance.

Andy, FG2

I mean it's not a big challenge, but directly adding it into the computer ... is fiddly, it's a step... It's not an insurmountable step but it adds to the ... difficulty, well, not difficulty, but you know, adds to the whole process.

Lee, FG5

In summary, this theme identified clinicians' time limitations and the need to prioritise their workloads. If clinicians did not prioritise data entry, then it would not be done. Clinicians also recognised the need for more staffing to ensure registry success. Suggestions ranged from registry clinical champions and registry coordinators, to additional clerical staff for data entry. A few systems and processes were highlighted for change, which could improve efficiency and therefore increase time available for data entry.

4.4 Theme Two - The dichotomy of registries: advantages and apprehensions

Interestingly, whilst staff described lack of time as a universal barrier to clinical staff entering data, participants still reported seeing value in having a SCI registry and were enthusiastic about what the data could provide. The second theme, *The dichotomy of registries: advantages and apprehensions*, explores two sub-themes: clinician-identified benefits a SCI registry can bring, followed by their suspicions and apprehensions. It covers the perceived purpose and value of a SCI registry, the positives of its use, the desire clinicians have to see it succeed, as well as the concerns clinicians raise.

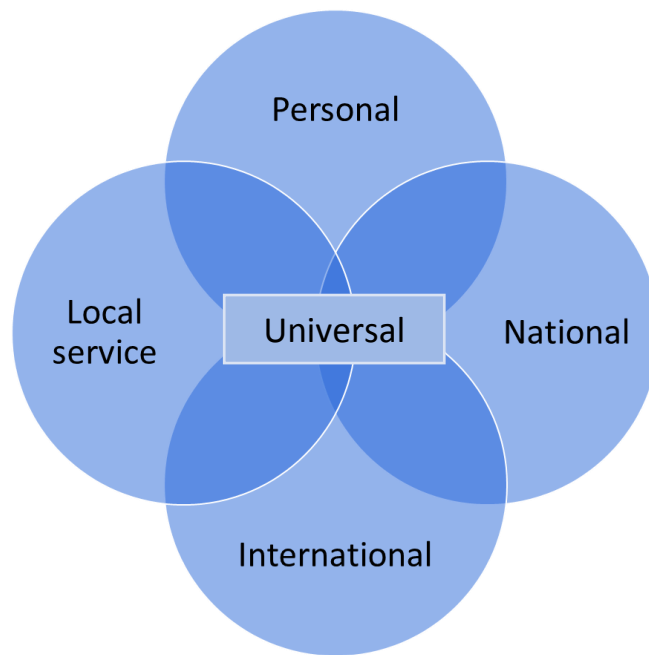


Figure 10: Categories of registry benefits identified by participants: personal, local service, national, international and universal

4.4.1 Benefits a registry can bring

In the first sub-theme, participants describe many benefits of having a SCI registry. This wide-ranging list can be grouped into personal, local service, national, and international benefits. As some benefits could be applied across all four areas, a fifth category, universal benefits, was created ([Figure 10](#)).

4.4.1.1 Personal benefits

A few participants believed it would make them question what they did, drive change, and ultimately become better practitioners as a result. Lee (FG5) said:

To have information that allows you to critique or examine your care is important, and I think, you know, if you just practised without actually analysing then I think you could be blindly ignorant to your performance, so I think personally it's important.

4.4.1.2 Local service benefits

All participants perceived the registry could be used as an analytical tool for the BSU. Many felt it could be used to assess the BSU's performance, using outcomes such as complication rates and length of stay, reviewing the unit against itself or other units.

It gives you opportunities to compare your complication rates etcetera, your length of stay, all these kind of things, which are important parameters and also, you know, measure your outcome measures, you can compare it with other similarly placed units and so it's like a self-scrutinising tool to some extent as well, as to how you're performing...

Shannon, FG2

Some stated different disciplines would find it useful, depending on what questions they wanted answered. The majority of medical participants believed the registry would influence their daily practice. They saw it as a powerful tool for research, but also in education for patients, family, and staff. A range of participants saw the registry as a planning tool, helping to identify service needs along the lines of staffing, budgets, and funding.

4.4.1.3 National benefits

When looking at national benefits, a few participants referred to a recent push for national consistency across both NZ spinal units through the SCI Action Plan. Some thought a registry may identify cultural differences, such as rehabilitation approaches, between the two units. Although one participant queried the value in this comparison, stating it may be completely unnecessary to compare, but felt it was important to establish the registry's purpose first.

I'm not sufficiently educated to think to, to come up with reasons for why I'd like to compare my unit with another unit, you know. It may be completely superfluous, unimportant to compare, so I think it's up to the registry to say what do you want it for?

Gabriel, FG4

Others saw the registry data supporting arguments for more funding through identification of national trends and highlighting an increase in need due to these trends. A few saw this as a way of justifying and supporting change in our national service delivery.

New Zealand's uniqueness was also discussed with NZ having a "multicultural, pretty active, dynamic, very small population" (Cameron, FG1), and how inequalities in both ethnicity and funding of SCI in NZ could be

unique. Māori and Pacific Islanders anecdotally appear to be highly represented in the NZ SCI population, whilst the disparities between our two funding streams (ACC and Ministry of Health) were a source of concern for many. Some felt the registry would help highlight and address these longstanding inequalities.

We have this unique Ministry of Health/ACC system and I think it would be quite interesting...to see some of that longitudinal stuff... and probably, you know, over a long period of time, might actually give us some arguments for changing some of the disparities between those systems.

Cameron, FG1

Having access to their own NZ-based data, as opposed to international data, was also seen to be of value to some clinicians.

4.4.1.4 International benefits

Many recognised the international benefits of a registry. Participants identified benefits associated with being on the world stage, which they felt the registry could do. They saw registries addressing the long-term goal of improving the worldwide standard of treatment and care for those with an SCI. Participants identified that the registry could aid in collaboration and research opportunities between NZ and other countries, which could lead to development of international best practice SCI guidelines and standards.

Ultimately it should provide, I think everyone in the world that's interested in this area, with... a best practice standard for lots of things to do with spinal cord injury.

Gabriel, FG4

4.4.1.5 Universal benefits

There were a few benefits that had personal, local, national, and international advantages. The universal benefit of improving patient outcomes was observed by all participants, representing all disciplines. Participants identified a registry could provide the ultimate goal of improving research, systems, service and therefore, outcomes for those with SCI.

Isn't the overall benefit of having the registry so that we can improve patient outcomes and patient care, based on what we learn from the data and our research?

Drew, FG3

Many participants supported the idea of registry research or data guiding current practice. Pat (FG2) synthesised the local and national benefits by stating:

The registry could help... by identifying areas for improvement in service strategy, by identifying ways in which practice could be improved to improve patient outcomes directly, by looking at, you know, I guess even higher up, legislation that could help with improving patient outcomes and participation.

Pat, FG2

Gabriel (FG4) agreed, by comparing treatments, interventions, and strategies between countries, practice changes could be affected internationally:

[The registry] could also supply us with perhaps ideas as to what sort of treatment might work best if you collect enough data. And so you could then compare treatments or any other thing, just interventions, management strategies in the acute phase or the rehab phase or the post-rehab phase between different countries...

Most participants linked the registry with research. They associated the registry with research activities, but not something they personally would be involved in. Many participants identified that SCI research requires collaboration, especially in NZ, where numbers are small. Some saw the registry as a way to promote collaboration with other units, both within NZ and internationally. By liaising with the RHSCIR, the medical team in particular felt the association provided more favourable opportunities for ongoing collaboration, especially regarding research.

You are on a world stage as soon as you are part of an endeavour like this, so with this comes lots of research, collaborative kind of processes come out of it, as in you enhance collaboration, you have more ties with different units who then think of you when ... they're looking at a research project and so you become a site which they would be interested in.

Shannon, FG2

Some saw the registry as a source of data that was easily accessible and supplied useful information. Participants felt gathering this data would allow them to effectively plan for the future. Andy (FG2) felt they could not be proactive “unless we capture what’s going on now”. Some acknowledged there was a lack of information currently, which the registry could resolve. The collection of information longitudinally was seen as a benefit – making it objective, rather than anecdotal. The data could then be used to objectively answer questions.

Well, people can’t do research or come to conclusions, look at forward planning, you know, without some kind of collection of information. If no one collects the information then there’s no ability, it’s all anecdotal, isn’t it? ... It separates subjective from objective, it’s objective data, as opposed to what our subjective thoughts are.

Mackenzie, FG3

In summary, a wide-ranging series of benefits, from personal to international, were described and every participant perceived benefits of an SCI registry at the BSU.

All participants appeared keen for it to succeed. One focus group’s thoughts were summarised by Taylor (FG2) who stated the registry was a “massive positive...I want to see it fly, like I want it to work”. Jessie (FG1) supported this by saying a NZ SCI registry was “way overdue”. Lee (FG5) stated it was “incredibly important” and registries succeed for a number of reasons, as summed up by the list of benefits clinicians reported. Lee said it was important to personally critique treatment clinicians gave; to have a tool to analyse the spinal unit’s performance; and from the patients’ perspective, ensure what happens to them is optimised now and in the future.

However, it seemed, despite positive affirmations regarding benefits across all groups, these were often followed by a tentative “but...”.

I'm a big believer in outcome measures and the registry but I sometimes wonder if that time spent is taking me away from doing something else that is equally or more important.

Jessie, FG1

I'm pro the registry and I'm pro collecting the data but, I struggle to do it, I struggle to actually be able to do it physically.

Jules, FG1

This led to discussions dominated by suspicions and apprehension, which forms the next sub-theme.

4.4.2 Suspicion and apprehension

Mackenzie (FG3) stated, "It's a database, a database of information that can be used for other information projects... a necessary evil". This statement summed up many of the clinicians' thoughts about the registry pilot – they felt it was a necessary project and tool, but it came at a heavy price, hence the "evil" connotation. Jules (FG1) stated:

I can see the value in it and everything, but it's the lack of support that we get, without [staffing], ... it's finding the time so we can actually do it justice and do it properly.

Shannon (FG2) pointed out "there's no easy answers to these things and the pilot was an eye opener", due to the complex nature of clinician data entry.

Clinicians reported they did not feel the registry would have any direct benefit or relevance for them. As a result, they appeared reluctant to personally engage in ensuring the registry's success. Cameron (FG1) felt:

If I'm not going to go on and do study, the registry is just something out there collecting data, it doesn't really have any practical relevance to me... I just think that people will ... have some negative feeling to it, ... 'cos they're not gonna use it, they're entering data that they're going to have no use for, ... some people might be at the end of their career and they're never going to use this information, or do you know where I'm trying to go with that? Do you know like, 'cos they're never gonna use it for study, they're never gonna advocate for a change in funding, you know, they're never gonna look at it from a management point of view, a research point of view, they're just entering data for somebody else's benefit.

Others expanded on this, stating if clinicians felt it was not relevant to them, then they would be less likely to comply or be involved with data entry, which could impact on the registry's longevity. Several were clear to note it was essential the purpose of the registry was set at the beginning, to ensure the information collected was guided by the scope, was useful to clinicians, and not overabundant and unwieldy.

You've got to be very clear about what you want your registry to do from the outset and then that will guide what information you collect and I think that's very important, otherwise you get into a situation where you're collecting a whole gamut of information without a clear purpose and reason.

Lee, FG5

The topic of data quality featured throughout the focus groups. Participants discussed the need for accurate, consistent, complete, and reliable data for it to be valuable. Some were concerned if a complete set of data was not completed for all patients, then the data would be invalid or biased. Many felt data needed to be reliable and accurate to ensure what comes out of the registry is trustworthy. Clinicians identified the issue of multiple sources of data within the clinical records, which could lead to potential inaccuracies. They felt data needed to come from an accurate, consistent source. There was also concern regarding who was going to be responsible for entering the data and how it was to be regulated. Lee (FG5) stated:

It's maintaining accurate data input and a consistent reliable data input, so the registry is only good if you've got a complete set of data points, or as near complete as possible, and the data's accurately collected.

A few participants believed the registry should collect internationally agreed and validated outcome measures. Some stated the registry needed the ability to evolve over time to ensure it reflected progressive thinking, both now and in the future.

Another concern shared by participants was the misinterpretation of registry data. Jessie (FG1) was keen to ensure the results would have a narrative, as

previous experience with the BSU's database, SpinData, showed results can be misleading without it.

Others felt the registry and its data were seen as "a bunch of numbers and dates and times" (Mackenzie, FG3). A few felt this was not valuable, and served very little purpose. However, many participants felt it was how the data were used that could lead to benefits.

You have to use the data usefully... There's no point just collecting data and no one doing anything with it, so in terms of the register, it's the use of the register that ultimately leads to better outcomes.

Drew, FG3

This was often mentioned in association with the database SpinData, with most linking it with failure. Despite only small number of participants having past experience with SpinData, it dominated focus group discussion. It appeared even those who had not used SpinData were aware of its trials and tribulations on the ward.

There's no point in spending all the money and time of having a registry though, if it doesn't get used, because I'm just visualising another giant SpinData that sits there so someone can go 'Oh, you know, we built this registry, isn't this wonderful? Tick' and then it sits there and it's just something in a computer with a bunch of information and never ever gets used.

Kerry, FG4

They felt SpinData had not been utilised to good effect and feared repeating the same mistakes with the RHSCIR.

You have to define what you want to collect and stick to it because otherwise it just becomes too big, and we've seen that - the previous SpinData failed really because of that reason. We were collecting too much information.

Shannon, FG2

Concern was raised about the burden it may place on patients. As mentioned in [section 4.3.3](#), with the demand for information came the need to perform repetitive assessments and tests. This was achieved with multiple disciplines

potentially doing the same type of assessment, unnecessarily putting patients through the same process many times.

Jamie (FG4) felt the registry could be seen in a negative light if it was not explained to clinicians properly. Jamie, along with other participants, felt there were suspicions that information from the registry could be used for purposes such as justifying decreasing staffing levels on the ward.

If people think that it's gonna be used to take away nurses because we're not getting the outcome measures, or it's showing that we're not getting the patients through or anything like that, it's gonna get people's backs up.

Jamie, FG4

In summary, this theme demonstrated the dichotomy felt by participants over the use of a registry in their practice. High value was placed on the multiple benefits it could potentially bring, however there remained a strong sense of apprehension and concern around their involvement in the data collection and entry, as well as the use of the data from the registry.

4.5 Theme Three - Engaging the clinician

The third theme, *Engaging the clinician*, explores concepts related to the need to involve clinicians throughout the implementation and use of a registry. It looks at what changes clinicians think are needed for successful interaction with registries, whether data entry falls into their roles and how important understanding and practicality are for clinicians.

The sub-themes which fall under this theme include the following: clinician buy in – engagement and understanding; we didn't become clinicians to be administrators; clinicians' willingness to change; and finally, incorporate it into practice.

4.5.1 Clinician buy-in, engagement and understanding

There was a clear indication clinicians felt changes being implemented in the service were dictated from those in authority, without engaging those on the

clinical floor. Participants discussed feelings of unfairness; things were being led and decided by service managers and clinical directors, without consulting staff. There was a sense of the clinicians' voice not being heard and not being involved in the direction of the service. They felt their valuable insight was not being tapped into and had resigned themselves to this fact:

You need to feel like you're included and something's going to some higher power that you never see and that you've actually got some influence, you can actually have an effect and some influence in the process because if you feel like you're being impacted upon but have no actual say, then you go to that feeling of, 'what's the point, then, our word never counts anyway'.

Dale, FG3

Drew (FG3) went on to state, "clinical-based research is great, but it can't all be on the back of the clinician." It was felt if a registry coordinator took the role of promoting research using registry data, it would facilitate interaction and involvement with the clinicians.

We need someone to co-ordinate it, so if you've got a research co-ordinator then they would be having meetings with each discipline and asking the disciplines, asking the service, 'what do we want to look at this year from this data?'

Drew, FG3

Participants enthusiastic about the registry felt there was reluctance from other clinicians to be involved. They felt those who did not engage did not understand what the registry's purpose was. Gabriel (FG4) was a reluctant clinician, and the comment, "I don't actually know what this registry is meant to serve", supported this theory. Lee (FG5) postulated that once clinicians understood registry benefits and why they were doing this, they would be more engaged and would not need to be driven to enter data.

...to engage them, I think, they've gotta understand its value either to them, or to the institution, or to the patients, and only when they understand that value will they buy into it.

Lee, FG5

Many deemed feedback as essential. They felt the lack of feedback needed to be addressed to improve clinician engagement and buy-in.

And you question how that helps our clinical practice and how it helps the patient? That information's never funnelled back to us.

Taylor, FG2

A few suggested buy-in and excitement could be promoted through feedback: by alerting them to what is being collected, what the data are being used for, and the long-term possibility of supporting a change in practice. Kerry (FG4) stated, "not everyone is au fait with registries and all the data". A few felt it provided an opportunity for ongoing discussion with clinicians around registry improvements or education.

Another point raised was how clinicians were approached for comment on the pilot. There was a suggestion a survey via email was not the best way to garner opinion, as they don't even remember getting "that" email and were more likely to "just push delete" (Mackenzie, FG3). Focus groups were suggested as a positive alternative method of communication, as it would encourage team collaboration, inspire discussion, and promote collective decisions.

4.5.2 We didn't become clinicians to be administrators

The next sub-theme highlighted clinicians' perceptions of becoming more involved with administration tasks. For clinicians, data entry into the registry was seen as an extra task, over and above their current job description.

We didn't really become clinicians to be administrators, do you know? That's sometimes what I feel ... I feel like I'm an administrator at least half the week, I didn't sign up to do that.

Cameron, FG1

Some resolutely felt that data entry was outside their current role:

You were asking, 'do you see it as your duty?' My answer is nearly, almost categorically, not in the present set up, no way, because data entry takes time, commitment. I'm not paid for this at the moment... Now if somebody was to say data entry is now one of your duties, I'd change to another hospital. That's my simple answer. That's how strongly I feel.

Gabriel, FG4

Clerical staff also voiced their concerns about clinicians entering data, based on their experience with BSU's SpinData. Clerical staff were keen to highlight the challenges surrounding busy clinicians and the need to chase up incomplete forms. Alex (FG2) stated:

The biggest challenge is consistency in data gathering and input.... Because if you don't get everything then you've lost the whole purpose... that was the biggest frustration with SpinData.

However, some clinicians acknowledged it was important they enter some data, as long as it was explicit and clinically relevant to them. They thought clinicians had the appropriate knowledge-base for data in their area, whilst the more generic data points, such as dates of admission and discharge, could be suitably delegated to a non-clinical staff member.

So, identifying what data is important, making sure they're inputting data that's important to them, making sure that they recognise that they're the best person to input that data because it requires some interpretation, and making sure that any data that doesn't require them specifically, you know, we look at other ways of getting that data so that they're not overburdened... and if you recognise the value of it, why you're doing it, and you recognise that there's no one else that's better than you at doing it...

Lee, FG5

4.5.3 Clinicians' willingness to change

The next sub-theme addressed the participants' awareness that something will need to change for it to be successful.

'Cos all the information that the registry is looking to collect, is already being collected... it's just fragmented, so we just need to centralise how we're inputting it and how we're recording it, into one spot.

Taylor, FG2

Participants identified they would need to be flexible and willing to implement a change in practice for this to work. They admitted it was possible, and they were willing, but that change was always difficult to achieve in a publicly-funded hospital.

The concept that registry data collection and entry will be compulsory for the BSU met with some differing opinions. One was unsure the word “compulsory” should be used, as “it puts a connotation on it that there is no choice” (Lee, FG5). One felt that as we were being paid for it “there’s accountability with it now, so it has to be done, there’s no two ways about it” (Shannon, FG2). Some were resigned that this was “something that we’re gonna have to do, I guess” (Jules, FG1). Meanwhile, others suggested, if it was compulsory, there needed to be allocated support provided to ensure its completion.

I think when you do things, like the pilot was voluntary, so, to some degree, and you did it willingly and enthusiastically, and you made time, and I didn’t mind doing that, but as soon as you put something in that’s compulsory, you want to be supported to do something.

Jessie, FG1

In summary, Theme Three highlighted the clinicians’ lack of engagement with the registry pilot, which ultimately led to poor buy-in. There was a sense of disempowerment regarding decisions made by senior management that impacted on clinicians without consultation. There were mixed responses regarding whether data entry was part of a clinician’s role, but acknowledgement they were the best personnel to interpret some of the data entered. Clinicians felt something would need to change before data entry by clinicians was successful.

5 DISCUSSION

5.1 Overview

This study explored clinicians' perceptions and understandings of registries, and aimed to establish what influenced clinicians entering registry data during a feasibility pilot project. The collective findings of this study indicate clinician data entry into a registry is complex, influenced by numerous elements, and is encapsulated in three themes, as described in [Chapter 4](#). Theme One, *I don't have enough time*, addresses the issue of time limitations clinicians face and their need to prioritise data entry into a registry. Theme Two, *The dichotomy of registries: advantages and apprehensions*, reflects on clinicians' contrasting views regarding registry benefits as opposed to the suspicions and apprehensions clinicians have. Theme Three, *Engaging the clinician*, refers to the need to involve clinicians throughout the registry design, implementation, and use phases. Whilst each of these themes is distinct, they have common elements which are dynamically related.

This study identified various barriers appearing to impact on a clinician's prioritisation of data entry over other tasks. Lack of time was the primary and most prevalent concern for all participants. Responsibility fell on the clinicians to incorporate registry data entry into their usual workday. My findings suggest clinicians needed to consider data entry as a priority if they were to enter data into the registry. Clinicians' attitude towards the registry can influence this prioritisation, and their mind-set and attitude are susceptible to several influences. Participants' previous experiences with registries or databases had both positive and negative influences on the prioritisation and data entry. Perceived difficulties influencing data entry included: it being outside their clinical role, role overload, and the fact it was a feasibility pilot held over a brief timeframe. Clinicians also demonstrated a lack of engagement

throughout the piloting phase of the registry, which appeared to have influenced their buy-in and ultimately, the degree of data entry completion. Several suggestions on how to improve this were made by the participating clinicians. Despite the barriers to data entry, all participants were positive about the potential benefits the registry brought to the SCI community; locally, nationally, and internationally. However, not many saw personal benefits, and even less participants appeared invested enough to make the data entry process work.

In this chapter, common elements from the themes regarding participants' perceptions and experiences will be synthesised and discussed with reference to relevant literature. Clinician attitude and prioritisation, influences on clinicians, and the ability of clinicians to change their behaviour will all be considered. Following this, implications for future practice will be highlighted, and the limitations and strengths of this study will be discussed, along with personal reflections. A final summary will complete this thesis.

5.2 Multiple influences effecting data entry prioritisation

Findings from this study illustrated clinicians felt they were too busy to incorporate registry data entry into their clinical workload. The main issues influencing data entry being prioritised into their workday were: clinician attitude, previous experiences, it was a feasibility project, they did not consider it part of their role, and that they had not been adequately consulted or engaged throughout the project.

Behavioural science has provided a range of well-developed and tested models of human behaviour that can be used to inform healthcare implementation research (Fleming et al., 2014; Godin, Belanger-Gravel, Eccles, & Grimshaw, 2008; Gupta, Boland, & Aron, 2017; Hrisos et al., 2008a, 2008b; Lehman, Greener, & Simpson, 2002; Nilsen, 2015; Simpson, 2002). Individual decisions regarding whether clinicians adopt a new behaviour can be assessed and then

targeted to help improve change behaviour. One prominent model with predictive use is the Theory of Planned Behaviour (TPB) (Ajzen, 1991). A central feature of the TPB is the individual's intention to perform a given behaviour. Intentions encompass an individual's motivational influences, including "indications of how hard people are willing to try, of how much an effort they are planning to exert, in order to perform the behaviour" (Ajzen, 1991, p. 181). The TPB framework suggests three determinants of intention: 1) attitude towards the behaviour (whether it be favourable or unfavourable); 2) subjective norm (the social pressure to perform or not perform the behaviour); and 3) perceived behavioural control (the perceived ease or difficulty of the behaviour, incorporating previous experience plus anticipated impediments and barriers) ([Figure 11](#)).

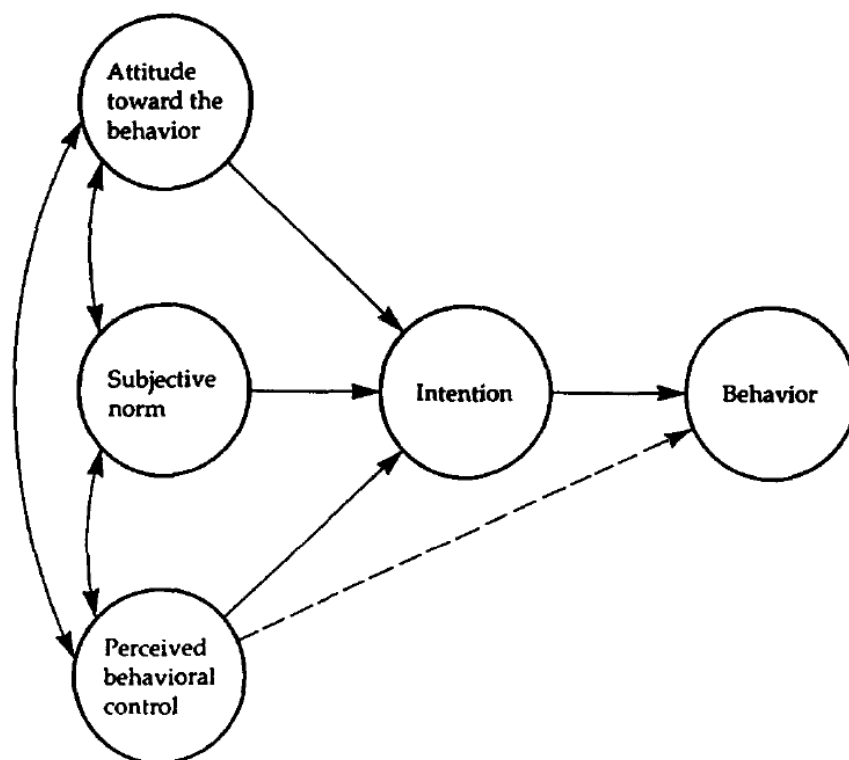


Figure 11: The Theory of Planned Behaviour (Ajzen, 1991, p. 182)

Generally, if a person's attitude and subjective norm is positive, and they perceive behavioural control, the higher the likelihood is that they intend to engage, and the task is more likely to be performed (Ajzen, 1991). Ajzen's (1991) framework supports my findings that participants' prioritisation was influenced by their attitude, previous experiences, and perceived difficulties. The remainder of this chapter will consider these elements which impacted on clinicians' data entry efforts during the feasibility project.

5.2.1 Clinician attitude

In this current study, clinicians described universal benefits of having a SCI registry in NZ. They were able to identify many areas of benefit; locally, nationally, and internationally. It was clear they understood the potential of a national registry. There were more perceived clinical local benefits mentioned, for example improved patient outcomes through using registry data and potential changes to make workflows more efficient. However, most struggled to identify useful aspects of the registry that would help on a personal level such as assisting with competency development, evaluating treatment through audit, and career progression. When asked whether there was benefit to them, the response was divided.

A few senior clinicians saw the registry as a tool they deemed useful and powerful for them personally. They listed multiple benefits of a SCI registry for them and were keen to see it progress. This was however, at odds with the low number of patient data entries they completed throughout the pilot period. This suggests whilst they held it in high esteem, they were unwilling to personally participate in data entry to make it a success. It is possible they saw their more junior members of staff as those who would be responsible for entering data.

In contrast, others saw no personal benefit at all. They viewed the registry as something someone else was doing, which was not going to be useful for them

as clinicians. Many perceived the registry as a pure research tool, nothing more. It also became clear the clinicians did not feel they were included in the potential research opportunities on the ward. Some saw the registry as an opportunity to include clinicians in potentially relevant SCI research, but did not want to be held responsible for making that research happen.

Prioritisation leads to intent, which leads to action. McLane (2005) suggests early assessment of clinicians' attitude prior to implementation of an EMR. Colligan et al. (2015) extends this by using a computer attitude score to predict nurse adaptation for EHR use. In this current study, attitudes were not assessed prior to the pilot project. If this had been done it may have potentially highlighted clinician attitudes and concerns, and provided additional valuable information for implementation of the registry into practice. It also may have improved communication, and provided the opportunity to address any of the clinicians' misconceptions.

The multiple steps required to adopt new knowledge are recognised by others. Complementing Ajzen's (1991) behaviour theory, Kayes, Cummins, Mudge, Larmer, and Babbage (2017) described the complex process to optimise knowledge uptake by clinicians in a rehabilitation setting. They described a multi-tiered, dynamic process that was potentially applicable to a range of populations, settings and contexts. By "making sense" of the perceived value or need, Kayes et al. (2017) found clinicians may, with support, "give it a go", if it is simple and intuitive. Once the clinicians had gained confidence and experienced success, they attempted to "put it into practice". The long-term consequences of this process, as also noted by Ajzen (1991), is behavioural change and embedding it into practice. By targeting these areas, there is potential to impact clinician attitude and promote change.

Attitude and the knowledge of what a registry can achieve is likely to have a large bearing on clinician mind-set, and on whether busy clinicians feel

motivated to enter data into a registry. Clinicians with a positive, can-do attitude have been shown to be more willing to bear the initial time costs to get benefits in EMR studies (Miller et al., 2004), and are more likely to adapt fast to a new EMR task (Colligan et al., 2015). Others suggest motivation is essential to initiate change (Lehman et al., 2002). Pagliari et al. (2003) believed the ability to influence clinicians' behavioural change is an essential part of facilitating stakeholder buy-in. The clinicians in this current study with a positive outlook and strong understanding of the registry appeared more likely to enter data, despite time limits, by prioritising data entry in their clinical day. Findings from other studies suggest the reverse is also true, in that those with a negative attitude to an EMR had lower levels of usage and found issues that arose more discouraging (McLane, 2005; Miller et al., 2004). A few participants were strongly opposed to clinician data entry and felt under stress, due to the amount expected of them clinically. These participants appeared to place data entry as a lower priority in their clinical workload. This was a major influencing issue as if clinicians did not prioritise it, it would be unlikely to be done.

Warsi et al. (2002) suggest more dedicated time for clinician data entry into a registry would be beneficial, after clinicians cited lack of time as a major barrier to data completion in a cancer registry. However, this current study's findings suggest if a clinician does not view it as a priority, even if adequate time or support is given, data entry performance is unlikely to change. A change in attitude and mind-set is more likely to have a long-term effect.

5.2.2 Previous experiences

In the current study, participants' previous experience with other registries or databases was a potential influence on data entry prioritisation. Whilst most had never had experience with the RHSCIR, they were all aware of, or had used, the BSU SpinData database. Many clinical staff questioned the purpose

and use of SpinData, projecting a general negative evaluation of the database. They identified ongoing SpinData issues and saw the tool as a failure, leading to less enthusiasm about developing or implementing something similar.

These negative perceptions regarding relevance and usefulness may have influenced participants' prioritisation of registry data entry during the pilot.

According to Ajzen's (1991) framework, previous experience is one determinant of perceived behavioural control. It not only refers to the beliefs developed through past experience with a behaviour, but is also influenced by second-hand information from experiences of acquaintances. This was evident in discussions regarding SpinData, as not all participants had personal experience with the database, yet most had heard from colleagues what appeared to be a negative attitude towards it. The negativity surrounding SpinData added a possible impediment to participants' perceived behavioural control, which in turn decreased their intention and prioritisation to perform the task.

The clerical staff in the focus groups were keen to highlight the previous issues with clinician data collection and entry. SpinData information was completed by clinicians on a paper template, which was then entered into the database by clerical staff. The clerical staff reported an ongoing struggle obtaining timely, completed templates for entry and they were unsurprised the same issues plagued the registry pilot. Barsoum et al. (2012) suggest that without oversight and a feedback system, compliance and participation rates are lower. This is consistent with issues reported at the BSU regarding SpinData: there was no strict management and no-one taking responsibility for it. It led to incomplete data sets, no feedback to clinicians, and poor utilisation of its data. These previous experiences were highlighted as a concern by many of the participants and provide some understanding as to their hesitancy to embrace the registry.

Conversely, one participant discussed their previous experience with the RHSCIR, the same registry used in the feasibility pilot. This previous experience positively shaped their involvement throughout the pilot period. They were familiar with it, its background, its potential and the processes being implemented here in NZ. They were very supportive of the registry and projected a positive outlook. Accordingly, it can be conferred they were personally engaged, which had a positive effect on their prioritisation of data entry during the pilot period. This correlates with Ajzen's (1991) theory, that with a positive attitude, subjective norm, and perceived behavioural control, the higher the engagement is, the more likely a task is to be completed.

Changing clinical practice is a difficult process. The implementation of the registry into participants' clinical practice was a challenge for many. Gupta et al. (2017) discuss the influence of experiences impacting on a physician's ability to abandon an outdated clinical practice to adopt a new one. Their findings build on change models, by suggesting personal characteristics, such as past experiences, personal biases and openness to change, will effect change.

Participants' past experience with SpinData, a potentially outdated clinical practice tool, may have negatively influenced their ability to adopt the newer RHSCIR. For example, if their SpinData experience or attitude was poor, this prior knowledge would make subsequent changes to practice more difficult.

5.2.3 Perceived difficulties

Participant-identified impediments and barriers were highlighted throughout the focus groups. The difficulties included role tensions, a perceived lack of engagement, and the fact it was a pilot project.

5.2.3.1 Role tensions

There were a few issues identified regarding participants' roles which caused tension. These issues were based around whether clinicians saw data entry as

part of their role, whether they were best to interpret pending data for the registry, and the additional stress data entry brought to their roles.

5.2.3.1.1 Not in my role, but better at interpretation

Clinicians' felt administration tasks were becoming more prevalent in their work days. Data entry into the registry was viewed by many as an additional administration task, which was deemed less of a priority than clinical tasks. Most did not see it as part of their role. They felt strongly that they were not sufficiently supported to ensure this extra task was achievable.

There were mixed perceptions about whether clinicians believed they were the best people for data entry. A few participants supported the view that clinicians were best to enter data, as long as the data points were relevant to them. It appeared there was general acceptance that, given time and support, clinicians were better at interpreting data points and as a result were more accurate than clerical staff when entering clinically-related data points.

Paxton et al. (2010) suggested, to maximise voluntary participation, minimal burden was required for clinicians. However, by limiting the data points Paxton et al. (2010) and Cadilhac et al. (2010) demonstrated this led to small data sets, which limited analysis. Data comes in many formats, as reported by Raghupathi and Raghupathi (2014). Semi-structured data, which was a data source for the registry pilot, needs a level of understanding and interpretation. It appears those clinically relevant data points would be best completed by clinicians and it could be assumed, as indicated by Lanzola et al. (2014) and Warsi et al. (2002), that trained clerical staff could be an alternative data entry option for the less interpretative elements, thus lessening the burden for clinicians. By involving clerical staff in the process, as Asare et al. (2015) suggests, it may aid the quality of data entered, most likely through decreasing the missing data component.

5.2.3.1.2 Role overload stress

Many participants reported an increase in expectations related to their roles in recent years. There was general acceptance there were too many tasks to be completed in their day. Simpson (2002) stated transferring knowledge into practice during tight economic times adds even more pressure to do more with less. Role overload is associated with burnout in healthcare professionals (Peiro, Gonzalez-Roma, Tordera, & Manas, 2001). The imbalance between demands and resources over time can result in chronic occupational stress and burnout. Peiro et al. (2001) investigated three role stressors which contributed to burnout amongst primary and mental health care professionals – role conflict, role ambiguity, and role overload. They set out to test the causal effects over time, on these three dimensions of burnout. Role overload was found to be significantly associated with emotional exhaustion. Recommended interventions included reducing and controlling role overload to prevent these negative experiences. In relation to data entry, Colligan et al. (2015) noted a substantial increase in workload for clinicians learning a relatively straight forward task on a new IT system. This current study's findings would seem to correlate with Peiro et al. (2001) and Colligan et al. (2015), with many participants expressing feelings of overload in relation to the steadily rising workload and infrastructural requirements associated with their clinical role. The increased workload in performing data entry into a new registry added to the clinicians' feeling of increased expectations on them and the stress which accompanied those expectations.

5.2.3.2 Lack of engagement

Another clinician-perceived difficulty was lack of engagement. It is difficult to ascertain if the low number of completed data sets during the piloting period were due to a lack of time or staffing, or a lack of enthusiasm secondary to previous experiences. As discussed previously, clinicians felt it was not within their clinical role, or they did not have time to dedicate to it. Another possible

influence could be a lack of clinician buy-in due to poor engagement with the project.

For the feasibility pilot project, key staff were identified and approached by email and invited to attend meetings to engage them in the implementation process. Despite this, some clinicians stated they did not feel engaged in the pilot, thus it could be assumed that this approach for input was inadequate to get engagement from clinical staff. Participants identified more constructive ways to engage clinicians, such as focus groups or workshops. They supported the idea of being involved with the registry decision-making process by contributing their experiences and clinical knowledge.

There were multiple references to what the participants perceived as the elite governance group, service managers or clinical directors making decisions without consulting or engaging clinicians. They felt they were being dictated to. Some clinicians gave the impression they were not happy with these personnel making decisions which would impact on their time and resources, without consultation. This general discord amongst clinicians suggested an unspoken rift between senior management and themselves. However, it was not the service managers or clinical directors that ultimately made this decision. The feasibility project was undertaken as part of the 5-year NZ SCI Action Plan. It was the action plan that was dictating the pilot project at the BSU. It appears that most participants were unaware of the action plan, and therefore were lacking knowledge of where this feasibility project was being driven from. Most clinicians would have benefited from explicit education regarding the feasibility project's background, but how that could have been effectively delivered is unknown. As participants suggested, focus groups or forums to discuss the action plan and its implications for the BSU was needed. This, in turn, may have improved staff buy-in during the project.

Some clinicians stated they wanted to be more involved with the registry implementation processes, especially regarding how it would impact them as clinicians, which is in line with Krall's (1995) commentary on EMR. If clinicians are going to invest in a project and change their practice as a result, they want to feel their opinion matters, that they are heard and valued. It was apparent in this current study, clinicians at the BSU did not feel they were valued and were therefore not invested in the pilot. Martikainen et al. (2012), along with McLane (2005), suggested early intervention with end users to help foster a more positive attitude long-term. Time was limited in the pilot, but if clinicians felt more involved, this may have impacted on engagement. Weiner (2009) believes involving end-users at the planning and implementation stage is a powerful tool to help people understand why the change is needed, important or worthwhile. He also suggests it is imperative to involve end-users to ensure the balance is met between demands, resources, and localised conditions. As Martikainen et al. (2012) posited, when clinicians are more invested, it is likely they would enter more data.

This engagement also extends to the type of data collected. By having clinicians actively involved in selecting data points to be collected, they would possibly be more likely to make an effort to ensure the clinically relevant data are entered. Participants were keen to know exactly what was being collected and why, believing they as clinicians should be involved in those decisions. By engaging clinicians at this stage, they could assist with standardising definitions and ensuring changes needed to data points remain current and relevant to practice (Asare et al., 2015).

Barsoum et al. (2012), Cadilhac et al. (2010) and Paxton et al. (2010) all suggest feedback throughout the process would show value and provide incentives for clinicians. Participants in this study stated they wanted feedback from the registry. This builds on their interest and willingness to be involved. They

commented that not everyone was au fait with registries and many recognised the potential interest data from the registry fed back to clinicians could offer. Promoting the registry on the ward through feedback could address any misconceptions, educate regarding what was being collected, and potentially promote change in practice. Feedback was not possible in the short pilot timeframe, which probably contributed to clinicians not feeling engaged.

Clinicians in this study also called for more support, someone who was visible and approachable on the ward. This, according to Miller et al. (2004), was the role of a clinical champion, who helped encourage others to adopt new systems. Herscovitch and Meyer (2002) believes those demonstrating championing behaviours promote the value of change to others within an organisation. Asare et al. (2015) builds on this, saying a clinician who serves as a registry data advocate, or champion, could improve data entry efforts and help guide relevant data points for registries. During the pilot, whilst key staff were identified to engage in the implementation process, there did not appear to be a clinician who was willing to be a clinical champion for the registry.

Clinical champions need to be a visible presence on the ward, someone who is on the floor amongst other staff regularly, to ensure constant interaction and encouragement. The role of clinical champion had not been established during the pilot project. It seems likely that being able to identify a willing clinical champion on top of what was already described as a heavy workload would have been challenging. This was just one area where there needed to be a shift in clinicians' thinking, but this takes time. The pilot timeframe was short so there may not have been time for necessary changes to be achieved, or for clinical champions to emerge.

5.2.3.3 It was a feasibility pilot project

A pilot is an important step taken prior to launching a larger scale project (Leon, Davis, & Kraemer, 2011). Pilot projects can guide, evaluate feasibility,

and promote good clinical practices. Whilst Leon et al. (2011) used randomised controlled trials as their example, they state the same principles are applied to all types of research studies, so this would include the BSU feasibility pilot on which this research was based. The fact that the registry was in a pilot phase only may have impacted on clinicians' commitment and prioritisation. They may not have prioritised data entry over other tasks. There is potential they saw the pilot as something temporary that may not be adopted long-term, thus were less likely to commit time and energy to it. Lack of commitment, according to Conner and Patterson (1982, p. 18), is "the most prevalent factor contributing to failed change projects".

Another issue was the sense of urgency. The short timeframe to trial the registries during the pilot gave a sense of urgency, which Weiner (2009) describes as unhelpful when uncertainty is high. Uncertainty surrounded the pilot project outcome and, this again, may have constrained clinicians' commitment and prioritisation.

5.3 Valued, but no responsibility taken

Despite the mixed perceptions about the registry, all clinicians wanted it to work. Clinician data entry into the registry, however, seemed to be a process most clinicians were not fully supportive of. They sat outside and expected the registry to work, but not necessarily through their input ([Figure 12](#)).

Clinicians identified benefits of the registry and clinician data entry but were not willing to commit to it. It appeared some clinicians put up barriers to data entry. While the barriers were not solid, they appeared immovable. There needed to be a conscious decision to make data entry a priority, before they made a commitment to be part of the registry, rather than sit outside it. It could be postulated if clinicians perceived the registry being of value, then they would be more likely to make data entry a priority. However, the findings of this study showed there are actually multiple influences that impact on

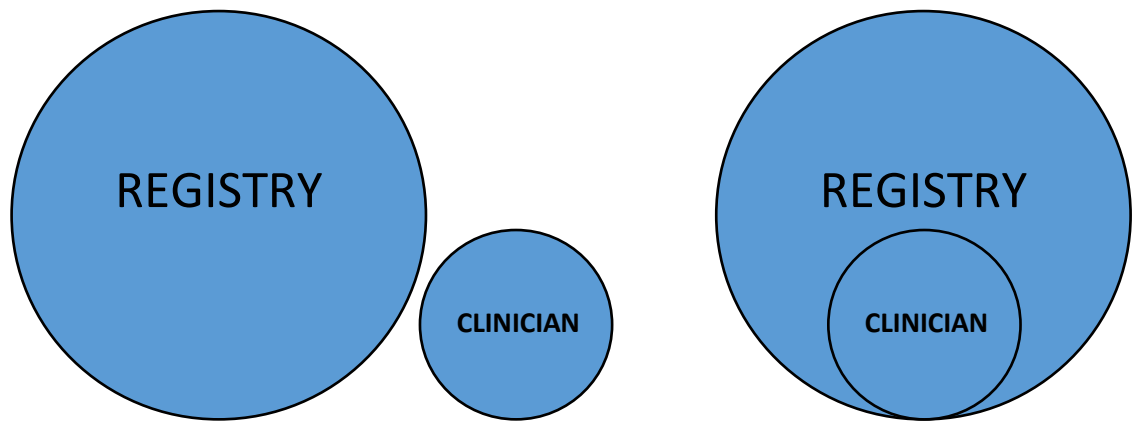


Figure 12: Where clinicians saw themselves in relation to the registry (left) and the ideal clinician-registry relationship (right).

clinicians' prioritisation of data entry into a registry. A clinician's attitude can be shaped by previous experiences, whether they see it as part of their role, their involvement in what was a feasibility pilot project, whether they felt engaged, and finally, whether they saw any benefit for themselves.

Change, as was highlighted in the focus groups, was considered difficult in publicly funded hospitals. Decisions about change can be at an individual level (see [section 5.2.1](#)), or at an organisational level. Given the feasibility pilot was undertaken at the BSU, it is necessary to not only look at personal change, but the effect of organisational change. Nilsen (2015) indicates that the physical environment or setting in which change takes place is becoming widely acknowledged as an important influence on implementation outcomes.

Greenhalgh, Robert, Macfarlane, Bate, and Kyriakidou (2004) suggest complex innovations in organisations have multiple components, and successful individual adoption is but one component. Whilst personal and organisational change is constant and universal, attention is needed to make it intentional and positive (Simpson, 2002). Simpson (2002) describes a change model for the introduction of new technologies or knowledge into a programme (see [Figure 13](#)). This framework assesses organisational functioning and readiness for

change. Simpson's goal was to develop a conceptual model which would aid transfer of research into practice, which he describes in four action steps:

- 1) Exposure; usually in the form of training (lecture, self-study, workshop, expert consultants);
- 2) Adoption; an intent to try an innovation. Often a leadership decision, but includes commitments made by staff members.
- 3) Implementation; a trial period of use to test feasibility.
- 4) Practice; incorporating into normal use and maintaining it.

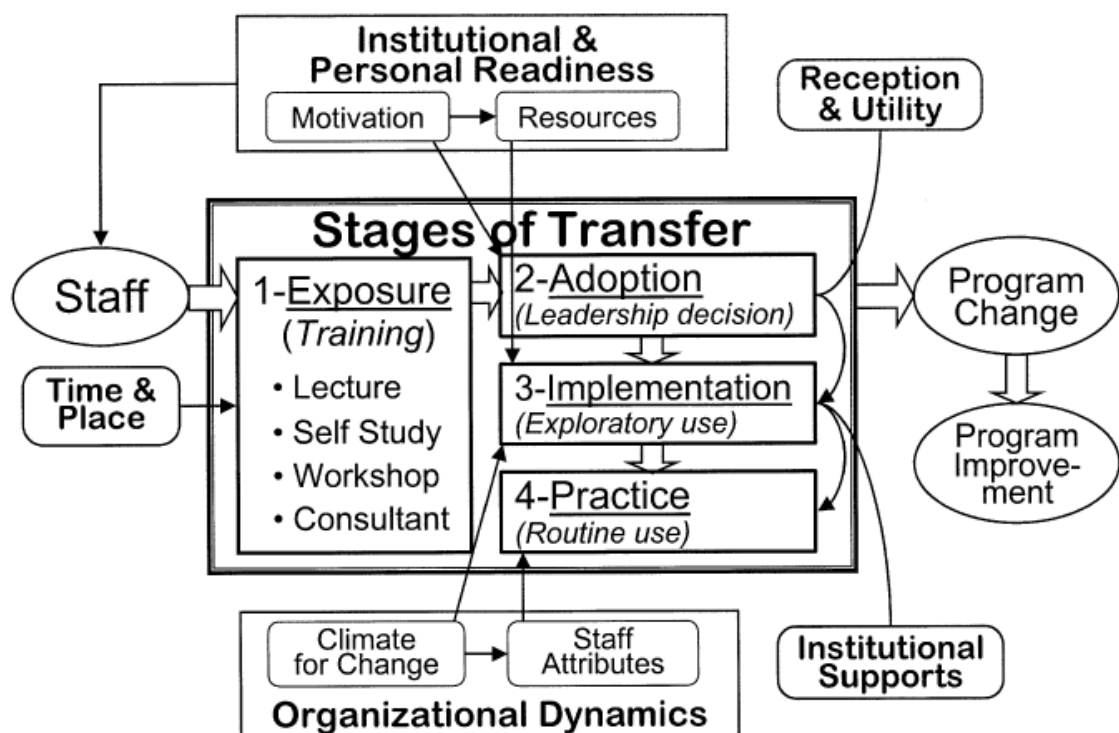


Figure 13: Programme change model (Simpson, 2002, p. 175)

Both Lehman et al. (2002) and Simpson (2002) highlight the effect of other variables on these steps and the resulting behaviour change, including institutional and personal readiness (motivation and resources), personality attributes of staff, and an organisation's climate for change. This current study was investigating participants involved in a feasibility pilot project, where the

first two steps of Simpson's model were not fully executed. 'Exposure' occurred through training sessions with key clinicians identified in the pilot. 'Adoption' was a decision made by the NZ Spinal Cord Action Plan group and Canterbury District Health Board leaders, yet commitment of clinical staff was not actively assessed, and their responses to the processes were mixed. The pilot was to trial and assess the suitability of the RHSCIR and another potential registry. The 'implementation' stage during the pilot was limited by time constraints.

Simpson (2002) highlights an organisation's inability to change is most likely due to organisational factors such as leadership attitudes, staff resources, organisational stress and management style. Lehman et al. (2002) further assesses the elements which impact on organisational readiness for change. Relevant items which impacted on the registry pilot, as indicated by participants, included institutional resources (staffing, training resources, computer access) and the organisational climate (staff cohesiveness, openness of communication, perceived stress and role overload, and openness to change). Weiner (2009) also itemises past experience as a contextual factor when determining an organisation's readiness for change. Positive past experience with change can foster organisational readiness. This belief is salient in relation to SpinData at the BSU, as the database's use may have conversely promoted a negative change influence at an organisational level.

Participants identified systems within the BSU that needed to change, which would lead to time being saved. Clearly making changes within the pilot period would not be possible, as altering well-established clinical systems and processes within a few months' timeframe would be extremely difficult. Imposing multiple changes within a limited timeframe would have the potential to alienate clinicians further. However, this study did stimulate clinicians to think differently about how these processes could be altered and

streamlined for a more productive, positive effect for all. It promoted discussion amongst both senior and junior clinicians, across multiple disciplines, which may result in future changes.

Whilst participants made their own decision whether it was a clinical priority for them, the 'readiness for change' at the BSU during the pilot was another issue and contributing factor. The time taken for changes to occur and become routine, would take longer than was set aside during the pilot.

A small number of participants showed enthusiasm and had high levels of data entry. Conversely, others had not entered much data, if any, as they felt it was beyond their role, had not been involved with the design, and did not feel they had been supported to do it. It seems most participants fell somewhere between these two stances.

At which end of the spectrum they sat was dependent on multiple influences. It can be assumed clinicians who were less engaged were more likely to have had poor previous experience with registries, did not feel it was as important as it was a pilot project, and felt it was not within their role. They also were less likely to see immediate clinical or personal benefits. As a result, they did not prioritise or commit to enter data into the registry. In contrast to this, those with higher engagement probably had a positive previous experience, embraced the pilot project, felt they were the best person for the job, and saw immediate clinical benefits. As a result, they prioritised and entered data into the registry.

As the pilot project had a short duration (12 months), it may be clinicians needed more time to make individual decisions to move them towards the more positive side of the spectrum, which is central to clinical change adoption. Clinicians may find change challenging or difficult within the existing environment. It appears support for clinician data entry, such as dedicated hours or extra staffing, combined with education and feedback, are needed to

decrease barriers. This organisational change may assist with the prioritisation and transition during registry planning, implementation and use.

5.4 Implications for future practice and research

Having established multiple influences on clinicians' prioritisation of data entry into a registry, this research can offer the following recommendations to aid those wanting to pursue clinician data entry.

5.4.1 Involve clinicians early to positively affect attitude

In order to have a positive influence, this research has supported others stipulating early clinician involvement is critical (Cadilhac et al., 2010; Krall, 1995; McLane, 2005; Pagliari et al., 2003). This has the potential to affect attitude, and therefore promote personal change.

As has been demonstrated throughout this study, clinicians are keen to be involved and, by including them in the initial stages, their attitude towards data entry into a registry is likely to be more positive. It appears BSU clinicians were aware of the benefits a registry can provide, however, many had associated negative experiences with a previous database prior to the pilot project. By educating the wider service as to the benefits and potential uses, it would help improve clinician buy-in and decrease the misunderstandings of its use. Research has shown, the more positive the clinician, the more likely they are to buy-in and enter data (Miller et al., 2004).

As a result of this study, the desire for clinicians to be involved in understanding and developing the scope and purpose of the registry was discovered. During the focus groups, clinicians requested input into creating focal areas of interest and selecting pertinent data points to be included in the registry. As this study has shown, clinicians are more likely to be positive about data entry when it is relevant to their practice. Mindful allocation of data points are needed to ensure data not requiring interpretation can be given to a non-clinical team member or specific registry coordinator. This ensures data

entered by clinicians are clinically relevant to them, thus removing an irrelevant data entry task. Another issue raised was burden and, if the data points are kept narrow and relevant, the buy-in would likely be improved. Conversely, if the data points are too few that meaningful clinical information is not able to be abstracted, then not only would analysis be limited, but clinician buy-in could be lowered.

In line with burden was the integration of data entry into their day. Involving clinicians in the incorporation of this additional task, rather than it being imposed upon them by those in authority, would give the opportunity to streamline and amalgamate with current practices. It would highlight issues early and provide an opportunity to address these potential barriers.

The way in which clinicians are approached for involvement is also important. Throughout a clinician's busy work day, emails can be read and forgotten, or simply missed. This study showed email was not the ideal method of engagement. A more interactive approach, such as focus groups or workshops, early in the process is more likely to improve understanding, collaboration and promote buy-in. Explicit involvement, rather than learning or hearing of projects via osmosis, is preferred. Whilst focus groups or workshops can be deemed high-cost due to combined hours of clinicians' time, the ability to share ideas and provide potential solutions would be a worthwhile investment early on.

5.4.2 Clinicians need representing at governance level also

Clinicians regard their time as a highly-prized commodity. When something is imposed that impacts on their valuable time, the effect is negative. This research has shown clinicians want to be involved and felt more consultation was required. A clinical representative on the governance group may be an option to engage clinicians' perspectives and highlight the impact of decisions on their work. This is likely to avoid the top-down negativity associated with

senior management and governance groups and improve clinical staff's understanding of registry processes. A clinical representative could ensure this knowledge was filtered down to clinical staff on the floor. This is valid across all levels of implementing a new process.

5.4.3 Specific roles and staffing required

There was a strong desire from clinicians to see specific roles established and extra staffing for registry data entry. There are multiple ways this support could be achieved. Participants offered three potential, highly desirable solutions. They need to be dedicated, clearly defined, and yet remain adaptable to situations, such as registry size and location.

1. Extra clinical staff to ensure clinical tasks are completed, as well as allowing clinicians designated time to complete the data entry within their role. The job descriptions need to be clear in stipulating the role clinicians would play in data entry.
2. The identification of clinical champions and use of them to promote data entry, the registry and its uses. There is a need to identify clinicians who are visible and approachable on the floor, who are positive and able to assist others. This would assist with developing a positive organisational change environment, increasing the likelihood of individual behaviour change.
3. A registry coordinator role to ensure day-to-day running of the registry was attended to, as well as providing potential data entry personnel. It would also create a consistent point of contact for any issues raised, as well as prompting clinicians to enter data when needed.

5.4.4 Provide feedback

Whilst feedback was not possible in the pilot project timeframe, staff identified feedback as beneficial to aid buy-in and build enthusiasm for its potential uses. This was supported by Barsoum et al. (2012), Cadilhac et al. (2010) and Paxton

et al. (2010), who suggest feedback would promote a registry's value, which ultimately leads to increased incentive for clinician data entry. Feedback would inform clinicians what data was being collected, why it was being collected and, over the long-term, see a potential change in practice. Feedback would also promote the registry data for use in research and potentially encourage clinicians to be involved in such endeavours.

5.5 Personal reflections

To ensure validity and rigour for this study, it was important to be aware of one's own position and methods. In terms of my position, I had an 'insider' status because I had not only worked as coordinator for the feasibility pilot, but also had a background as a physiotherapist at the BSU for the past 16 years ([section 3.2.2](#)). Reflecting on my experience of the present study, I felt this 'insider' status could have influenced the research in two ways. Firstly, the participants were very forthcoming in discussing their experience during the pilot. Having been a clinician at the BSU for the past 16 years, I had worked with many of the participants for a significant amount of time. We were colleagues and had an open, easy dialogue. It is possible they opened up to me more, as they saw me as a clinical colleague, and thought I would understand their concerns more than someone who did not know the pilot or workplace as well.

Secondly, because I have been a physiotherapist or coordinator working with all the participants, this created an interesting challenge for the focus groups. I was very aware that they could see me as a registry coordinator from my day-to-day job. I had just concluded the pilot project and was in the process of applying for the registry coordinator role. Hay-Smith, Brown, Anderson, and Treharne (2016) recently reviewed literature regarding health research involving clinician-researchers. They examined the issues surrounding dual-role experiences and developed a framework to help address the ethical and

methodological challenges. This is where the dual role of clinician-researcher came into play, or more accurately in my case, colleague-researcher dual role. Several themes they identified were pertinent to my study. These were clinical queries, perceived agenda, research or therapy, suspicion and holding back, and over-identification. The clinical queries theme described discomfort arising, with participants asking questions of clinician-researchers, but they feel unable to respond due to believing their hands are tied for fear of blurring roles or affecting data quality. When participants asked me questions I felt were directed at the coordinator, I was careful to remove myself and state my position as a researcher and unwillingness to affect the direction of conversation. There was just one occasion in a focus group, where my neutral observer had to intervene to reiterate my statement that I was not there to answer their queries, but to ascertain their perspectives and opinions.

Another theme, perceived agenda, may occur when participants ask a question of the researcher and the researcher perceives an agenda lying behind the question. At times throughout the focus groups, I felt I was being asked to acknowledge unmet needs, offer a second opinion, or acknowledge the extra burden of data entry for clinicians. I felt concerned if I was to respond it would create a false expectation for the participants. I was conscious, especially after the first focus group in discussion with my observer, of not agreeing or disagreeing with the participants, when they were looking for agreement or confirmation. This not only shut the conversation flow down, but potentially indicated my personal thoughts to participants. I was therefore careful to structure my responses to be neutral and to delve further into their answers such as, "That is interesting – tell me more about that", or "tell me why that is important to you". I was careful not to lead conversation with my personal opinions.

The third relevant theme to my study identified by Hay-Smith et al. (2016), was research or therapy? Being known by participants as both a clinician and a researcher is enough for researchers to experience dual-role disquiet. Many of my participants made specific reference to sessions I had with them as the pilot coordinator, regarding data entry during the pilot. I was sure to make my position as a researcher clear prior to every focus group. I did not wear Canterbury District Health Board clothing or identification. I performed the focus groups outside of the BSU. However, it appeared participants still had difficulty distinguishing the clinician-clinician collegial relationship from the clinician-researcher relationship. Potentially the participants may have expected a coordinator response that was not part of the research. I did feel, at times, there were unanswered participant queries, or I wanted to address, clarify or challenge some statements given due to the knowledge I had as a coordinator. Hay-Smith et al. (2016) report many accounts of researchers left with a persistent “sense of unfinished business” after the research is complete, due to their clinician perspectives, which I could identify with.

The theme of suspicion and holding back discusses the researcher’s suspicion that participants are holding something back. Participants may be suspicious of the purpose of the research and, as a result, their responses may be guarded. Conversely, researchers can be reassured by participants willing to be critical of “services, people or care”, as this indicates they are not holding back (Hay-Smith et al., 2016, p. 10). It appears my participants were not holding back regarding the negative aspects of the pilot project and clinician data entry. It was, however, difficult to hear the criticisms due to my personal association with the pilot project. In this respect, I made a particular effort to remain neutral. I attempted to resist my instincts to defend the feasibility pilot process but instead try and understand the “what” and “why” behind the criticism.

The final theme relevant to my study was over-identification. The researcher can over-identify with their clinical self, or with the clinical environment within the area they are conducting the research. That is, the researcher can feel too close to have an outsider perspective in the research and be blind to the phenomenon or setting being studied. Having a neutral observer present in all my focus groups certainly helped with this. Another way of combating this was to keep a personal journal during my research. I also answered my interview questions prior to data collection ([Appendix F](#)). This enabled me and my supervisors to consider my personal experience throughout the research and what influence it had, if any.

5.6 Limitations and strengths of this study

The aim of this study was not to generate findings that were generalisable to a wide audience. Generalisability was not expected of this qualitative study, however it is hoped it would enhance understanding and contribute to the body of evidence regarding clinician data entry. Braun and Clarke (2013) discuss the more appropriate concept of transferability. It refers to the earlier works of Lincoln and Guba (1985) and the extent to which findings can be transferred to other groups of people and contexts. To ensure transferability is possible, it is essential details of the study (participants, settings, circumstances) are specifically documented to enable others to ascertain if the findings would be relevant to their area of interest. I believe I have outlined this study's details sufficiently for interested parties to determine how the findings may apply to their own setting.

This study was based on a feasibility pilot project. As discussed in [section 5.2.3.3](#), there are limitations associated with this, including the likelihood of clinicians not prioritising data entry due to the brevity of the pilot. This was one question that was not specifically asked during the focus groups, which may have confirmed my assumptions. I noted in my journal during data

analysis the potential line of questioning regarding the pilot nature of the project. “The registry feasibility project was a pilot. How did that impact on your data entry efforts?” If this was pursued, it may have heralded more valuable insight.

Other potential areas of further investigation were noted in my journal. These lines of enquiry may have been valuable to probe:

- Championing. Who did clinicians see as a champion? And what qualities did they expect a champion to have?
- Engagement. The clinicians reported a lack of engagement, yet many were approached for input during the feasibility pilot. Did clinicians *perceive* this lack of engagement? It appears there may have been an element of clinician apathy, and a need to actively engage in opportunities offered to them.
- Usefulness as a clinician. Why do clinicians not feel the registry is useful? How could a registry be useful to clinicians?
- Clinical change. Will the registry drive or force change? In what light will that be seen by clinicians?

As an inexperienced researcher, I was learning throughout the entire research process. The focus groups were an area of rapid learning and skill development. Initially, it felt like participants were trying to give me facts and were looking for the right answer. I discussed this issue in the previous section ([section 5.5](#)), when looking at perceived agenda. I learnt not to agree with participants, but attempted to illicit a more personal response, rather than participants looking for a factual, textbook answer. In addition, the initial question I asked of the first focus group came across as challenging clinicians’ understandings, and tended to promote more negative responses. The questions were reworded or reframed to be more neutral and less-challenging.

I aimed to promote discussion and learnt to accept awkward silences to allow them to think about their response and talk more on the subject. I also learnt to redirect queries by answering their questions with questions.

Another potential limitation was the focus group make-up. Due to clinical commitments, it was difficult to schedule times to suit all potential participants. Whilst two-thirds of eligible participants were involved, numbers made it difficult to structure groups other than by availability. Some groups may have had members dominate or lead discussion due to their seniority. This observation was noted in the discussion preceding one focus group, where a participant stated “we are in esteemed company today”, referring to the senior clinician in their group. Whilst it did not appear to prevent people discussing their reservations, it may well have had an impact.

Another issue was the inclusion of clerical staff. By having clerical staff in focus groups, it was my hope they would offer insight into their interaction with clinicians using an alternative database. However, the study’s aims and objectives were focused on the clinicians’ experiences, perspectives and influences. Whilst the semi-structured interview schedule was worded to include clerical staff in the discussion, and they participated regarding their SpinData experiences, their contribution to the study’s aims and objectives were less than I had anticipated. They gave support for clinicians having a dedicated registry staff member to assist data collection and ensuring full data completion.

Another limitation was the difficulty in finding relevant literature on the topic of clinician data entry into registries. The subject area was challenging due to the wide-range of terms and definitions used in healthcare and HIT. The exploration of relevant reference lists yielded many more articles. Searching for qualitative studies on clinician perspectives in electronic databases is

complex and I was unable to identify any in my specific area of interest. It may be my search terms were too narrow to detect relevant articles.

5.7 Final summary

Based on existing literature and findings from this study, I have shown clinician attitude and prioritisation of data entry into a registry is complex and influenced by many things. This study has given a clinicians' voice to the body of literature surrounding registry data entry. Time is a prominent barrier to data entry, however if clinicians did not prioritise data entry, they were unlikely to commit to and complete the task. Despite mixed perceptions and experiences, clinicians saw registry benefits and wanted the registry to succeed, but not necessarily through their own effort. They did not feel consulted or engaged in the registry pilot, but expressed a desire to be more involved throughout the registry process. Change is required at both a personal and organisational level to improve attitude and prioritisation, overcome any previous negative experiences, and to decrease perceived difficulties.

If clinician data entry is planned, I posit that clinicians should be involved at all stages of establishing a registry: design, implementation, and use. Influencing clinicians' attitude early potentially will have a positive impact on their data entry efforts, through improved prioritisation. Ensuring clinicians are represented at the governance level will support clinically relevant data points and minimise data entry impact. Further registry specific staffing, such as clinical champions and coordinators, are required to support clinicians to enable data entry. The provision of additional clinical staff would allow time for clinicians involved in data entry to gather, interpret and enter the information in dedicated time, rather than having to prioritise data entry over clinical tasks. Other less clinically relevant data points may be delegated to clerical staff. Ongoing and regular feedback from the registry is recommended to aid clinician buy-in and demonstrate the potential benefits of registry use.

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7 APPENDICES

Appendix A: Examples of data collected during the pilot

REGISTRY PILOT DATA POINTS	Persons responsible
Sociodemographic Name, Gender, Date of birth, National Health Identifier, Ethnicity, Relationship status, Height, Weight, Education level, Occupation, Smoking history, Alcohol consumption, Drug use, Living setting, Compensation	Coordinator
SCI details Traumatic: Injury Date/Time, Mechanism of injury, Geographic region, Emergency health services call/arrival, Glasgow Coma Scale, MRI date/time, traction, date mobilised into a wheelchair Or Non-traumatic: Aetiology	Coordinator/Medical
Neurology Assessment Initial, Acute, Rehab admission, Rehab discharge	Medical
Spine Diagnosis/Surgery Spinal column injury location/diagnosis. Surgical facility, Date/times, Surgeon, Procedure, Time from SCI to decompression	Surgeons
Respiratory Forced Vital Capacity, Tracheostomy, Ventilation	Physiotherapist/Medical/Coordinator
Past medical history Comorbidities	Medical
Complications Delirium, Urinary tract infection, Pneumonia Pressure injuries	Medical Nursing
Rehabilitation demographics Assistive Equipment Bladder emptying, Spasticity, Pain, General Self-Efficacy Scale, Services accessed as inpatient, Outpatient services post-discharge	Occupational therapist Coordinator
Functional outcomes 10 Metre Timed Walk, 6 Minute Walk Test, Berg Balance Scale SCIM (Self-Care, Respiration, Mobility, Sphincter Management)	Physiotherapist Occupational therapist/Physiotherapist/ Nursing
Facility Admission and discharge dates and times (all visits) Discharge destination	Coordinator

Key: MRI = Magnetic Resonance Imaging; SCI = Spinal Cord Injury; SCIM = Spinal Cord Independence Measure.

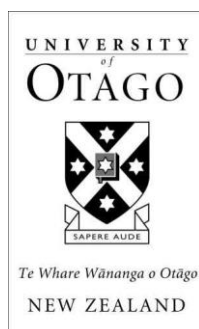
Appendix B: Feasibility pilot registry webpage

The following screenshot illustrates the feasibility pilot webpage. Each patient's study binder contains forms encompassing their spinal cord injury journey – initial, acute and rehabilitation phases. Multiple forms cover all data points relating to this one patient. The example below covers a small selection of acute forms. They are divided into disciplines and completeness is indicated under the form name.

The screenshot shows the 'Global Research Platform' interface for the 'New Zealand Rick Hansen SCI Registry - Pilot'. The top navigation bar includes a search bar with the text 'Search New Zealand Rick Hansen SCI ...', a 'Logout' button, and links for 'My studies', 'View reports', and 'FAQ'. Below the navigation bar, the page title 'New Zealand Rick Hansen SCI Registry - Pilot' is displayed, followed by links for 'Enroll a new participant', 'Find a participant', and 'Review share requests'. A row of buttons includes 'Delete', 'Share this participant', and 'Add a data collection point'. The main content area is titled 'Study ID (3)' and 'Study Binder'. It lists several forms organized into sections: 'Enrollment details' (BURWOOD SPINAL UNIT (BSU)), 'Enrollment - Coordinator' (BURWOOD SPINAL UNIT (BSU)), and 'Acute - Coordinator' (BURWOOD SPINAL UNIT (BSU)). Each form entry shows its title, a date (Nov 5), and a completion status (Completed, Incomplete, or Partially completed). The forms are: 'Coordinator: Enrollment Form (CRC-Enrollment Form)', 'Coordinator: End of Study (CRC-EOS)', 'Coordinator: Demographics (CRC-SP-Initial)', 'Medical Team: Christchurch Public Hospital Visit Details, Interventions (MED-VD&CI-NP C)', 'Medical Team: Other Pre-CPH/BSU Visit Details, Interventions (MED-VD&CI-NP O)', and 'Medical Team: Burwood Spinal Unit (BSU) Acute Visit Details (MED-VD-Acute)'.

Form Name	Discipline	Completion Status
Enrollment details	BURWOOD SPINAL UNIT (BSU)	
Enrollment - Coordinator	BURWOOD SPINAL UNIT (BSU)	
Coordinator: Enrollment Form (CRC-Enrollment Form)		Completed
Coordinator: End of Study (CRC-EOS)		Incomplete
Acute - Coordinator	BURWOOD SPINAL UNIT (BSU)	
Coordinator: Demographics (CRC-SP-Initial)		Completed
Acute - Medical Team	BURWOOD SPINAL UNIT (BSU)	
Medical Team: Christchurch Public Hospital Visit Details, Interventions (MED-VD&CI-NP C)		Partially completed
Medical Team: Other Pre-CPH/BSU Visit Details, Interventions (MED-VD&CI-NP O)		Completed
Medical Team: Burwood Spinal Unit (BSU) Acute Visit Details (MED-VD-Acute)		Incomplete

Appendix C: Participant information sheet and consent form



A RESEARCH STUDY OF BURWOOD SPINAL UNIT STAFF OPINIONS AND EXPERIENCES USING SCI REGISTRIES; AN INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this study. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the study?

A pilot project at the Burwood Spinal Unit (BSU) trialed the Rick Hansen Spinal Cord Injury Registry (RHSCIR) and collected data on all new acute patient admissions. The RHSCIR has just been accepted for adoption in both New Zealand (NZ) spinal units, and processes are underway to develop it for NZ use, incorporating it into daily practice. Information provided from this registry could be used for audit, planning, research and international comparisons.

To assist with our use of a national spinal cord impairment (SCI) registry, we are collecting information from BSU staff in regards to their experiences entering (or not entering) data into the RHSCIR or any other SCI registry. This will allow us to see how staff feel about registries in general and what they like and dislike about their use. Your feedback will assist in further streamlining the national roll out of a SCI registry, making it as user-friendly for staff as possible.

This study is being undertaken as part of the requirements for Tracey Croot's Master's thesis through the University of Otago.

What type of participants are being sought?

All staff, across all disciplines, who have been invited to enter data into the registry (whether they have entered data or not) will be approached, as well as those with experience in SCI registry/database data entry.

What will participants be asked to do?

Should you agree to take part in this study, you will be asked to participate in a focus group with three to eight other staff members. By participating in this focus group you will be able to tell us what you think, and therefore, influence the processes you may be using in the near future. It is not compulsory but we appreciate the feedback you have to offer. Each session will be led by Tracey Croot, who will ask questions to learn about your experiences with SCI registries.

In the event that the line of questioning develops in such a way that you feel hesitant or uncomfortable, you are reminded of your right to decline to answer any particular question(s) and you may withdraw from the study at any stage without any disadvantage to yourself of any kind.

When and where will this happen?

The focus groups will be held throughout March - July 2016. It is expected each session will take approximately 60-90 minutes. Sessions will be held at the Meeting Room in the Surgical Orthopaedic ward. Times will be set to ensure all shifts are covered and all staff have the opportunity to attend. Refreshments and snacks will be provided.

What data or information will be collected and what use will be made of it?

We aim to collect information on your experiences using or not using registries. Information obtained from the focus groups will hopefully identify both positive and negative experiences of staff using a registry. This will help us refine the process of incorporating a registry into the BSU and aims to take into account the issues raised through these focus groups.

The sessions will be video or digitally recorded and transcribed to allow the data to be analysed. The video is purely to ensure the transcripts are accurate (recording audio only makes it difficult to transcribe with a group of speakers). Only the transcriber and researcher will have access to this information.

Every attempt at anonymity will be made by removing staff names and using pseudonyms for transcribing. However, it may be possible for individuals / individual professions to be identified because of the small number of discipline-specific staff. If this occurs, the data will be grouped and results will be reported anonymously, ensuring you remain unidentifiable in the completed research study results.

Information obtained will be grouped into themes and you will have access to this if you wish, by contacting Tracey Croot. This de-identified information may be accessed by a typist, the Researcher and the Burwood Research Committee to facilitate development of a national SCI registry. Data generated in this study, but not reported, be made available for use in future research. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. The data, once collated, will be used in a University of Otago Masters' thesis.

This project involves an open-questioning technique. The general line of questioning includes your thoughts on having a registry here at the BSU, your personal experience

with the registry; how it impacted on your work and what you would improve or change. The precise nature of the questions which will be asked, have not been determined in advance, but will depend on the way in which the discussion develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the sessions, the Committee has not been able to review the precise questions to be used.

The data collected will be securely stored in such a way that only the Research Team has access to it. Data obtained as a result of the research will be retained for at least 10 years in secure storage. Any personal information held on the participants (such as digital recordings, after they have been transcribed) will be destroyed at the completion of the research.

What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:

Tracey Croot

University of Otago Master's student/researcher

Phone: 383 6850

Email: crotr280@student.otago.ac.nz

Dr Jennifer Dunn

University of Otago, Study supervisor

Department of Orthopaedic Surgery and Musculoskeletal Medicine.

Phone: 0211364079

Email: jennifer.dunn@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research, you may contact the Committee through the Human Ethics Committee Administrator (phone 03 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated, and you will be informed of the outcome.





CONSENT FORM FOR STUDY PARTICIPANTS

A RESEARCH STUDY OF STAFF OPINIONS AND EXPERIENCES USING SCI REGISTRIES

Principal Investigator:

Dr Jennifer Dunn

Jennifer.Dunn@otago.ac.nz

Phone: 0211364079

Once signed and returned to the research team, this form will be stored in a secure place for ten years.

Name of participant:

1. I have read the Participant Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Participant Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will be a part of a focus group that will be videoed and the video may be accessed by a third party for transcribing details. A script will be generated and held in a secure location.
7. I know that the focus group session will explore opinions and experiences of registry use and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable, I may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.

8. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
9. I understand that the results of the project may be published and be available in the University of Otago Library, and any personal identifying information will remain confidential between myself and the researcher during the study, and will not appear in any spoken or written report of the study.
10. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:

Date:

Appendix D: Demographic participant survey



A RESEARCH STUDY OF BURWOOD SPINAL UNIT STAFF OPINIONS AND EXPERIENCES USING SCI REGISTRIES; A SURVEY FOR PARTICIPANTS

Please answer the following questions to enable us to place you into the appropriate focus group. This information will also be used to collate our results into groups for analysis. Every attempt will be made to preserve your anonymity throughout this study.

1. Full name:

1. Age (please circle): 20-24 years 25-29 years 30-34 years 35-39 years
 40-44 years 45-49 years 50-54 years 55-60 years
 65+ years

3. Gender (please circle): Male Female

4. Ethnicity (please circle): NZ European
 Māori
 Samoan
 Cook Island Māori
 Tongan
 Niuean
 Chinese
 Indian
 Other (specify):

5. Discipline (please circle): Surgeon
 Rehab Consultant
 Registrar
 Nurse
 Physiotherapist
 Occupational therapist
 Social worker
 Clerical staff

6. Year of first professional qualification (if applicable):
7. Highest post-graduate qualification & year:
8. Years of experience in the Burwood Spinal Unit (please circle):
0 -1 year 2-4 years 5-9 years 10-14 years 15- 19 years 20 yrs+
9. Have you been invited to enter data into the Rick Hansen Spinal Cord Injury Registry (RHSCIR) (either online or in paper format)? (please circle) Yes / No
 - a. If yes, have you entered any information (either online or in paper format)? (please circle) Yes / No
 - b. If yes, approximate number of patients entered? (please circle)
1 2 3 4 5+
10. Any previous experience with an alternative registry/database? (please circle) Yes / No
 - a. If yes, please identify below:
☐ SpinData
☐ Upper Limb Surgery database
☐ Other. Please name:

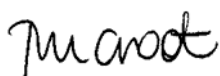
Preferred contact method (please circle): Phone Email

Phone number: Work Cell

Email address:

Many thanks for your time.

If you have any queries, please don't hesitate to ask.



Tracey Croot
University of Otago Master's Student
c/o Burwood Academy of Independent Living (BAIL)
Marshland Room
Burwood Hospital

crotr280@student.otago.ac.nz

Mob: 0211456300

Appendix E: Semi-structured focus group interview schedule

Welcome and thank you for attending.

The aim of this focus group is to discuss the use of a registry at the Burwood Spinal Unit. You have either been invited to input information this past year into the Rick Hansen Spinal Cord Injury Registry or been involved with SpinData. We appreciate your input as it is vital to understand the effect and impact on staff.

I am here today as a University of Otago student researcher. The information gathered here today will be collated and used for my Masters' Thesis. The summary will be presented to the BSU Research Group to aid our implementation of a national registry here at the BSU. Throughout this research we will make every attempt to preserve your anonymity.

Some ground rules: There are no right or wrong answers. We are interested in everyone's opinion and views. You are the expert on your experiences. Try to talk to each other, rather than just answering me. We would ask that you are clear when you speak and not to talk over or interrupt other members of the group. This is to ensure everyone has their say and makes it much easier for me to transcribe. We would ask that you respect those present and not discuss what is said here today outside of this room. Can I get you to switch your phones to silent please.

If you feel at all uncomfortable at any stage, you are welcome to leave. If you do, I will be in touch to see if you wish to participate in a one-on-one interview to ensure your opinion and experiences are recorded.

Thank you for signing the consent forms and for giving permission for this session to be digitally recorded. ##### is here today as my assistant, to support me and keep me on task! We think the session will go for just over an hour – maybe a bit longer.

Does anyone have any questions before we begin? **START RECORDING**

Just to do some introductions for the recording - If we go round the table and say your name and your role in the BSU, then tell me if you could have done anything else in life for a career, what would it have been?

The reason you are here today is help me explore your thoughts and opinions around registries. The objectives of my Master's are to:

1. Establish what staff feel about registries, and
2. Explore the factors that influence you in entering data into a registry.

I'm going to explore four areas, it's a semi-structured format, but this will be your discussion. I'm aiming to get some good discussion amongst the group and I'd encourage you to debate or disagree on things. It's actually helpful for me if you discuss amongst yourselves these points. There are no right or wrong answers.

Objectives:

1. What are clinician's perceptions and understandings of registries?

2. What influences clinicians entering data into an SCI registry?

1. If we think about registries in general – can you tell me what you feel a registry is? I'm not after a definition – just what your thoughts on what a registry is to you.

Possible prompts:

What type of information would you expect it to collect?

What is the purpose of a registry?

2. How do you feel about the role or purpose of a SCI registry?

For whom or why do you feel they can be beneficial?

For you? As a clinician, how would it be useful for you?

For the BSU?

For the NZ spinal impaired population?

For funders?

For researchers?

For whom and why do you feel there are challenges associated with SCI registries?

For you?

For the BSU?

For the NZ spinal impaired population?

For funders?

For researchers?

Why do you think it is important for a registry to be used in NZ?

Who could use this information?

How do you think we will use this information you have inputted?

3. Funding has been given for the RHSCIR to be NZ's national SCI registry and will be a compulsory data collection tool in the BSU from July this year. I'd like to explore the factors influencing staff entering data into a SCI registry.

To what extent do you feel entering data falls into your role? Why?

Did you think the information you were entering was appropriate to your area of work? Why?

What would you change about the information you were expected to enter?

What do you see as the benefits of clinician entering their own information?

Challenges?

How does it being compulsory make it different?

4. For those who haven't entered data into RHSCIR, given the info you have or experience with other data systems, can I get you to think about what the potential challenges and benefits of entering data into NZRHSCIR could be?

For those who have entered data into RHSCIR, can you tell me challenges or benefits you have experienced?

There was an expectation that entering information into the RHSCIR could be incorporated into your clinical day, how did that work for you?

Possible prompts: When did you fit it into your work day?

When in the patient journey did you input info?

Would you change this?

What factors made it easy/difficult for you to enter info in a timely way?

Were there ways in which other disciplines impacted on your info entry?

Would a prompt from a co-ordinator re info entry be beneficial?

If a new member of staff joins your team, what would you say to them about the registry?

About the process of entering information?

If raised: Given that every staff member has different levels of computer competency, tell me about the training for the RHSCIR. How do you feel about the training you received?

Possible prompts: What went well with the training?

What went less well with the training?

How would you improve it or change it?

What suggestions would you offer to improve the process for clinicians?

What are the main factors/issues stopping you from entering data?

What would need to change for you to enter data?

If you were fully resourced staff wise – what would the main challenges be?

What was the most important thing we covered today?

Were there any positive things for you personally that have come from using the registry?

Anything less positive you'd like to note?

I think that's basically all I had to ask of you. Has anyone got anything they'd like to say – any final thoughts, anything to follow up on, anything you feel we haven't covered?

Many thanks for your time. It is a very important part of the process to help us improve the process of registry use for staff so thank you for your thoughtful answers. We will be collating and summarising the data over the next few weeks. If you wish to know the results, then just contact me at any time.

Additional prompts:

Why?

What do you mean by that?

Tell me a little more about this...

Is there anything else?

Can you elaborate on that idea?

Would you explain that further?

Would you give me an example?

Do you have any examples of that?

Does anyone else see that differently?

Does anyone else agree?

I'm not sure I understand what you're saying...

That's a really interesting/valid point. Can we focus on the question...

I'm interested to know why you asked that question...

Has everyone had their say on this?

Appendix F: Reflection and self-completion of focus group semi-structured questions

Reflective consideration has been given to my background, personal opinions, as well as hopes and fears for the registry projects, with the aim of encouraging rigour and reflexivity regarding my own methods and analysis in this current study. My interest in the area of registries has simmered away since joining the Burwood Spinal Unit physiotherapy team in 2001. In those first few days of orientation, there was no officially known number of people who had a SCI in NZ each year, nor any details of their injuries or functional level. Instead, I was quoted overseas statistics and given anecdotal information. This surprised me.

Fourteen years later, I was given the opportunity to be a researcher for a feasibility study looking to trial two established international SCI registries for NZ. I was keen to be involved in what I saw as a valuable, overdue project. A registry had been discussed at the BSU since 1969, so to be a part of the drive to finally get this underway, with the backing of ACC and the two DHBs, was very appealing.

During the feasibility pilot it was obvious to me that some clinicians were strongly for the registry and their part in it, whilst others were not. This intrigued me and led to this study. I am an advocate for a NZ SCI registry. I also believe clinicians are the right people to enter some data as long as it does not remove them from important patient contact time. I was able to empathise with my participants as I had personally entered data into the registry, however, it did make me overly familiar with the topic which may have decreased the detail the participants discussed, as they would potentially have assumed I knew many clinician issues, as I was one of them. My experience may have been an influencer, but I used techniques to decrease my influence (as described in [section 5.5](#) and [5.6](#)).

The following questions were answered prior to the beginning of the focus group sessions. This gives insight to my orientation on the study subject. The semi-structured questions below are the first version developed, which on reflection, were modified after each focus group performed. The final questions can be seen in [Appendix E](#).

1. If we think about registries in general – can you tell me what you feel a registry is?

A record of people with the same condition or exposure, with pre-determined data points, for a pre-determined purpose. Tightly monitored and controlled. A highly useful tool.

2. How do you feel about the role or purpose of a SCI registry?

An overdue tool we can use to gather information on the NZ SCI population.

Give actual factual data, not anecdotal.

To help direct research, to find research participants, or to use data in research.

To help improve services i.e. journey, bed stays, staffing

To lend support to drive policies i.e. help decrease time from injury to surgery

To improve prevention through identifying trends

To help assess interventions/services

For education, using our own NZ data.

3. Funding has been given for the RHSCIR to be NZ's national SCI registry and will be a compulsory data collection tool in the BSU from July this year. I'd like to explore the factors influencing staff entering data into a SCI registry.

To what extent do you feel entering data falls into your role? Why?

Yes and no. Someone has to and I would like to do it if it was not too much of a burden or addition. If it was data we were already collecting or data the service felt was needed or useful, then yes. However, it would be beneficial to have support through dedicated time specifically set aside in our work day to allow registry data entry and dedicated forms/definitions/education to ensure accuracy.

4. For those who haven't entered data into RHSCIR, given the info you have or experience with other data systems, can I get you to think about what the potential challenges & benefits of entering data into NZRHSCIR could be?

For those who have entered data into RHSCIR, can you tell me challenges or benefits you have experienced?

Time – always pressure for notes, discharge paperwork, equipment requests.

Never enough time for everything.

Snowball effect – if I leave it, I forget it, I miss it.

Accessing information – need to modify forms to allow all recording on the same form.

Definitions – clarification is needed over the timeframes and when they apply to each patient.

Appendix G: Ethics approval letter

Academic Services
Manager, Academic Committees, Mr Gary Witte



H15/106

16 October 2015

Dr J Dunn

Department of Orthopaedic Surgery & Musculoskeletal Medicine (ChCh)

University of Otago, Christchurch

University of Otago Medical School

Dear Dr Dunn,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled **“The implementation of a spinal cord impairment registry into clinical practice at the Burwood Spinal Unit, New Zealand”**.

As a result of that consideration, the current status of your proposal is:- **Approved**

For your future reference, the Ethics Committee’s reference code for this project is:- **H15/106**.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

<http://www.otago.ac.nz/healthandsafety/index.html>

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

jo.farronediaz@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,



Mr Gary Witte

Manager, Academic Committees

Tel: 479 8256

Email: gary.witte@otago.ac.nz

c.c. Professor G Hooper Department of Orthopaedic Surgery & Musculoskeletal Medicine (ChCh)